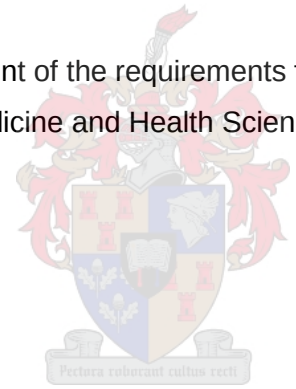
Adolescent-friendly services: Experiences of adolescents living with HIV attending healthcare services in Botha-Bothe District in Lesotho

Mamoferefere Tatapa Zim Mabandla

Thesis presented in partial fulfilment of the requirements for the degree of Master of Nursing Science in the Faculty of Medicine and Health Sciences at Stellenbosch University



Supervisor: Dr Talitha Crowley

March 2020

Declaration

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Abstract

Introduction

There is an increased focus on the promotion of health and wellbeing amongst adolescents. Adolescents living with HIV (ALHIV) need to access high-quality and comprehensive health services. Adolescent-friendly services are services which are easy to reach, are appealing, and are delivered in acceptable ways to adolescents, to meet their health needs. Considering the health of adolescents, the need for adolescent-friendly services was identified, to lessen the load of diseases and to decrease the number of deaths that occur amongst adolescents. The adolescent HIV burden is still a concern and countries are struggling to establish interventions that are effective for positively influencing HIV related outcomes in this group. There are few studies on the experiences of ALHIV about accessing health services in different countries and various health facilities. Little is known about adolescent-friendly services for ALHIV in the context of Lesotho.

Aim

The study aimed to explore and to describe the experiences of ALHIV regarding attending healthcare services in Botha-Bothe District Lesotho, in order to make recommendations towards improving adolescent-friendly services.

Method

A qualitative exploratory-descriptive research design was applied. The Health Research Ethics Committee (HREC) from Stellenbosch University and the Research Coordinating Unit (RCU) from the Lesotho Ministry of Health approved the study. Twelve ALHIV between the ages of fourteen (14) and nineteen (19), who were attending healthcare services at Baylor or Ngoajane health facilities and were aware of their HIV status, were purposively selected to participate in the study.

For adolescents under eighteen (18) years old, written informed adolescent assent and parental consent was obtained. Written informed consent was obtained from adolescents aged between eighteen and nineteen (18 and 19). Individual interviews were conducted by the researcher. The six steps of data analysis described by

Creswell were applied when analysing the data. The researcher ensured trustworthiness by adhering to the principles of confirmability, transferability, credibility and dependability.

Results

Five themes were identified: the social environment of the health facility, the physical environment of the health facility, services, support and expectations regarding healthcare services. Communication between the participants and the healthcare workers was challenging. It seemed that it was difficult to communicate effectively because of the generation gap and the adolescent stage of development. Healthcare workers were more likely to communicate in a consistent respectful manner if adolescents were adherent to treatment and care.

Health facilities do not have a dedicated space to allow adolescents to interact with peers and share their experiences. Services that adolescents use in the facilities are counseling and HIV care and treatment. Family members seemed to be involved minimally in the care and in the treatment of adolescents. Adolescents prefer services to be provided on a Friday after school, or on a Saturday when they are not attending school.

Conclusion

ALHIV need to access comprehensive adolescent-friendly services, as this may improve their health outcomes. The elements of adolescent-friendly services that could be improved include providing a dedicated space, the provision of age-appropriate educational materials, encouraging care partnerships and the training of healthcare workers to ensure technical and attitudinal competences, in providing healthcare services to adolescents.

Key words: Adolescent-friendly services, adolescence, adolescents living with HIV (ALHIV), and the experiences of ALHIV.

Opsomming

Agtergrond

Daar is 'n verhoogde fokus op die bevordering van gesondheid en welstand onder adolessente. Adolessente wat met MIV leef (ALMIV) moet toegang hê tot hoë gehalte en omvattende gesondheidsdienste. Adolessent-vriendelike dienste is dienste wat maklik is om te bereik, is aanloklik, en word gelewer in aanvaarbare maniere om in adolessente se gesondheidsbehoeftes te voorsien. Met inagneming van die gesondheid van adolessente, is die behoefte aan adolessent-vriendelike dienste geïdentifiseer, om die lading van siektes te verminder en om die aantal sterftes wat onder adolessente voorkom te verminder. Die adolessent MIV-las is steeds 'n bekommernis en lande sukkel om intervensies te vestig wat effektief is om die MIV-verwante uitkomste in hierdie groep positief te beïnvloed. Daar is min studies oor die ervaringe van ALMIV oor die toegang tot gesondheidsdienste in verskillende lande en verskeie gesondheidsfasiliteite. Min is bekend oor adolessent-vriendelike dienste vir ALMIV in die konteks van Lesotho.

Doel

Die studie het ten doel gehad om die ervaringe van ALMIV oor die bywoning van gesondheidsdienste in Botha-Bothe distrik Lesotho te verken en te beskryf, ten einde aanbevelings te maak om adolessent-vriendelike dienste te verbeter.

Metode

'n Kwalitatiewe verkennende-beskrywende navorsingsontwerp is toegepas. Die gesondheidsnavorsings etiekkomitee (GNEK) van die Universiteit Stellenbosch en die navorsing koördinerende eenheid (NKE) van die Lesotho ministerie van gesondheid het die studie goedgekeur. Twaalf ALMIV tussen die ouderdom van veertien (14) en negentien (19), wat gesondheidsdienste by Baylor of Ngoajane gesondheidsfasiliteite bygewoon het en van hul MIV-status bewus was, was doelbewus gekies om aan die studie deel te neem.

Vir adolessente onder agtien (18) jaar oud, is skriftelike ingeligte adolessente bekragtiging en ouer toestemming verkry. Skriftelike ingeligte toestemming is verkry

van adolessente tussen agtien en negentien (18 en 19). Individuele onderhoude is deur die navorser gedoen. Die ses stappe van data-analise wat deur Creswel beskryf is, is toegepas wanneer die data ontleed was. Die navorser het betroubaarheid verseker deur aan die beginsels geloofwaardigheid, bevestigbaarheid, oordraagbaarheid en bestendigheid, te voldoen.

Resultate

Vyf temas is geïdentifiseer: die sosiale omgewing van die gesondheidfasiliteit, die fisiese omgewing van die gesondheidfasiliteit, dienste, ondersteuning en verwagtinge met betrekking tot gesondheidsdienste. Kommunikasie tussen die deelnemers en die gesondheidsorgwerkers was uitdagend. Dit was moeilik om effektief te kommunikeer as gevolg van die generasie gaping en die adolessente se stadium van ontwikkeling. Gesondheidswerkers was meer geneig om in 'n konsekwente respekvolle wyse te kommunikeer as adolessente toegewy was aan behandeling en sorg.

Gesondheidsfasiliteite het nie 'n toegewyde ruimte om adolessente toe te laat om met eweknieë te kommunikeer en hul ervarings te deel nie. Dienste wat adolessente in die fasiliteite gebruik, is berading en MIV sorg en behandeling. Gesinslede was minimaal betrokke in die sorg en in die behandeling van adolessente. Adolessente verkies dat dienste op 'n Vrydag na skool, of op 'n Saterdag wanneer hulle nie skool bywoon nie, aangebied word.

Slotsom

Omvattende adolessent-vriendelike dienste moet aan adolessente gelewer word, aangesien dit hul gesondheidsuitkomste kan verbeter. Die elemente van adolessent-vriendelike dienste wat verbeter kan word, sluit in die verskaffing van 'n toegewyde ruimte, die voorsiening van ouderdoms toepaslike opvoedkundige materiale, aanmoediging van sorgvennootskappe en die opleiding van gesondheidsorgwerkers in tegniese- en houdings-vaardighede, in die verskaffing van gesondheidsorg dienste aan adolessente.

Sleutelwoorde: Adolessent-vriendelike dienste, adolessensie, adolessente wat met MIV leef (ALMIV), en die ervarings van ALMIV.

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Abbreviations

AIDS	Acquired immune deficiency syndrome
ART	Antiretroviral treatment
ALHIV	Adolescents living with HIV
BIPAI	Baylor international paediatric AIDS initiative
DHIS 2	District health information system version 2
HIV	Human immunodeficiency virus
UNAIDS	United Nations Joint Programme on AIDS
UNICEF	United Nation Children Emergency Fund
UNFPA	United Nations Fund for Population Activities
US NGO	United States of America Non-Government Organization

CHAPTER 1

THE FOUNDATION OF THE STUDY

1.1 INTRODUCTION

Globally, there is an increased focus on the promotion of health and well-being amongst adolescents, in order to improve their survival (Laski, 2015:1). Adolescents with knowledge, life skills and healthy productive lives who attained human rights satisfaction tend to have better health. Adolescents need to access quality and comprehensive healthcare services, so that their needs are addressed.

Adolescence is the developmental period characterised by bodily and cognitive changes. The individual is neither a child nor an adult, ranging between the ages of ten (10) and nineteen (19) (World Health Organization (WHO), 2012:1). It is a transitional state of social, rational and behavioural development (United Nations Programme on HIV/AIDS (UNAIDS), 2016:13).

The WHO (2012:2), the United Nations Children's Fund (UNICEF) and the United Nations National Population Fund (UNFPA) agreed on the goals of preventing health problems, promoting healthy development and responding to increasing adolescent problems, in order to meet adolescents needs. Therefore, health services provision should be friendly so that adolescents will be willing to utilize these services (WHO, 2012:7).

According to the UNAIDS fact sheet (2019:16), 37.9 million people were living with HIV (PLHIV) in 2018. Of these, 1.7 million were children below 15 years of age. A large proportion of PLHIV reside in Eastern and Southern Africa (20.6 million) (UNAIDS, 2019:17). South Africa had a National HIV prevalence of twenty-point four percent (20.4%) in the age group fifteen to forty-nine (15 to 49). In Lesotho, the HIV prevalence was twenty-three-point six percent (23.6%) in the same age group (UNAIDS, 2019:48). The Lesotho Population-Based HIV Impact Assessment (LePHIA, 2017:1) stipulated that the HIV prevalence was 29.7% among women aged fifteen to forty-nine (15 to 49) and 19.1% among men aged fifteen to forty-nine (15 to 49). This indicated a higher HIV prevalence amongst women.

The aim of the study was to explore the experiences of adolescents living with HIV (ALHIV) regarding attending healthcare services in the Botha-Bothe District in Lesotho. In this chapter, a brief discussion of the rationale for conducting the study, the problem statement, the research question, the aim of the study, the objectives of the study, and the research methodology is provided.

1.2 RATIONALE

Botha-Bothe district had the highest percentage at twenty-five percent (25%) of teenage pregnancy amongst the ten districts in Lesotho (Lesotho Demographic and Health Survey, 2014:249). Although there may be various factors contributing to the high rate, it may indicate that adolescent health services were not accessible and not meeting the needs of adolescents. Being adolescent-friendly means providing non-restrictive services, easily negotiated access and attractive facilities. Moreover, the facility should provide services in suitable hours and involve adolescents in planning such services (Tanner, Philbin, Duval, Ellen, Kapogiannis & Fortenberry, 2014:2).

Adolescent-friendly services should be focused on both the physical and on the social environment. The physical environment comprises space, learning and leisure facilities and the social environment comprises healthcare workers who are responsive to the needs of the adolescent, clear policies and procedures that do not restrict the provision of health services and community support in the provision of services (Tanner et al., 2014:1).

The services need to be complete, delivering a necessary package, including appropriate prevention, care, treatment and support for adolescents. Services should be delivered by trained and inspired healthcare workers who are technically competent. They should know how to communicate with adolescents without being judgemental (WHO, 2010:34). Adolescents should be included in planning their healthcare services. Services should be close to schools to make them more convenient and these services should be linked with youth clubs and schools (Gage, Do & Grant, 2017:14). Adolescents living with HIV need psychological support to combat the fear of stigma and to avoid self-stigmatization. They need sex and sexuality education that is simple and age appropriate, to avoid confusion when identifying their sexual orientation. Moreover, some adolescents have low socio-economic status due to the loss of parents (UNICEF, 2016:14). These adolescents

therefore have unique needs and they may be more likely to access HIV services and navigate the healthcare system on their own.

Dawood (2015:2) in the article entitled “Adolescent HIV Treatment Issues in South Africa, concludes that there are still barriers to the development and the sustainability of complete care for adolescents in South Africa. However, in Lesotho, there is limited documentation or research evidence regarding adolescent healthcare services. Therefore, the researcher was interested in exploring and describing the experiences of ALHIV who attend healthcare services. The adolescent HIV burden is still a concern and countries are struggling to establish interventions that are effective for positively influencing HIV related outcomes in this group (Gage, Do & Grant, 2017:1). The study contributes information on how to improve adolescent-friendly services for ALHIV in the context of Lesotho.

1.3 PROBLEM STATEMENT

While working at a primary health care facility from 2008 to 2016, the researcher observed that adolescents had preferences and needs. Adolescents who were obtaining their antiretroviral treatment (ART) at the facility preferred to come at a time that suited them, and they generally ignored the provided follow-up dates. They did not communicate to the healthcare workers that they preferred a different date. They sometimes came in the afternoon, especially on Fridays, when the schools are closed, knowing that on those days and times, that there are fewer or no clients waiting for services. Adolescents preferred to come at times when they would not have to wait long for services, which could be because they tried to avoid being seen. Adolescents preferred to be treated with respect and by someone who is considerate of their confidentiality (WHO, 2012:5). Their behaviour may therefore be due to the services previously not having been adolescent-friendly or not meeting their needs.

The researcher further observed that adolescents were not utilising the provided services optimally. This limited utilization may lead to more health problems and may compromise their healthy development. Although the researcher had observed that adolescents who live with HIV tend to attend healthcare appointments poorly, this was only an anecdotal observation since no statistical data was collected on the number of adolescents who defaulted on treatment in Lesotho.

Since 2005, when ART were introduced into the district, the registers or the tools used to collect data about the program did not collect information regarding adolescents' retention into care. This information is vital to track the progress of adolescents on ART and it is an indicator of their service utilisation. The absence of this data and the lack of research studies related to the experiences of adolescents utilising healthcare services in Lesotho, necessitated further investigation. The researcher was interested in exploring the experiences of adolescents living with HIV, regarding the physical environment, the social environment and their expectation from the services. The new information that was provided by this study will be applied to improve adolescent health services in the district because the expectation is that the results will be transferable.

1.4 RESEARCH QUESTION

What are the experiences of adolescents living with HIV, regarding attending healthcare services in the Botha-Bothe District in Lesotho?

1.5 RESEARCH AIM

The aim of the study was to explore and describe the experiences of adolescents living with HIV regarding attending healthcare services in Botha-Bothe District in Lesotho, in order to make recommendations towards improving adolescent-friendly services.

1.6 RESEARCH OBJECTIVES

The objectives of the study were to:

- Describe the experiences of adolescents living with HIV regarding the physical environment of the health facility.
- Describe the experiences of adolescents regarding the social environment and their interaction with healthcare workers.
- Determine the types of healthcare services utilised by adolescents living with HIV.
- Identify adolescents' expectations regarding healthcare services

1.7 THE RESEARCH METHODOLOGY

A qualitative research methodology was used for this study. Figure 1 below depicts an overview of the study methodology. A more detailed description is provided in Chapter 3.

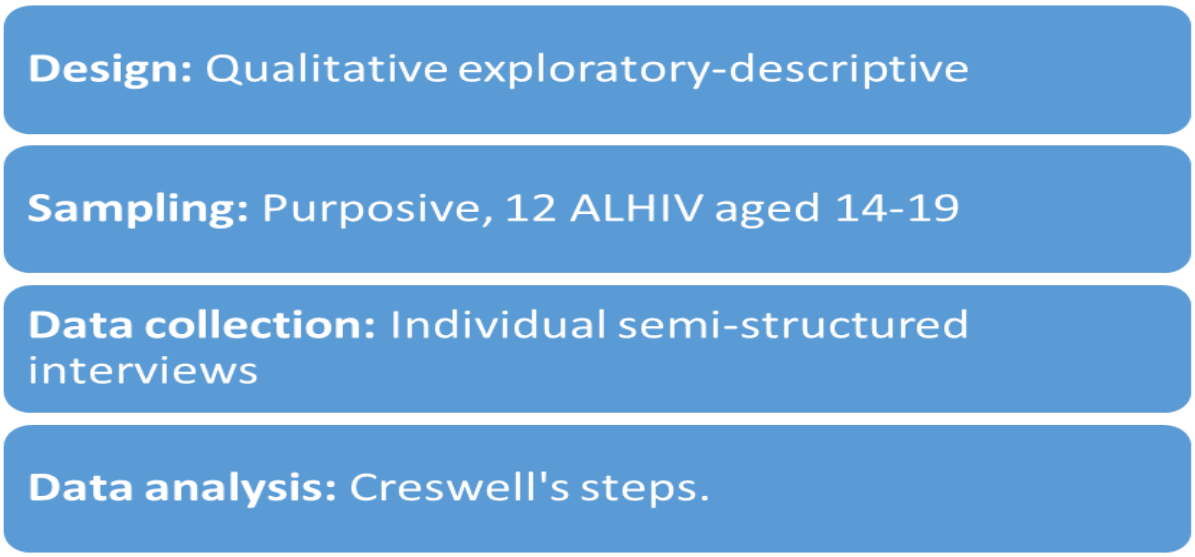

Figure 1.1 Overview of the Study Methodology

1.7.1 The research design

An exploratory-descriptive research design was applied as the purpose of the study was to describe the experiences of participants (Grove, Gray & Burns, 2015:69). The exploratory-descriptive design was the most appropriate as the researcher was interested in new information specific to the context of Lesotho, that would be applied to improve adolescent health services in the district.

1.7.2 The study setting

Lesotho is a mountain kingdom in Southern Africa. It is a small developing country that is divided into ten districts. Among those ten districts, the first one is the Botha-Bothe district in the northern part of the kingdom (Figure 1.1). There are twelve health facilities, two hospitals and ten health centres. One hospital and two health centres belong to the Christian Health Association of Lesotho while the rest are owned by the government of Lesotho. Ngoajane Health Facility is owned by the government of Lesotho. Baylor Health Facility is owned by the government of Lesotho but is managed through a partnership with the United States of America

non-governmental organization (US NGO) called the Baylor international paediatrics AIDS Initiative (BIPAI) (Figure 1.2).

These two facilities were purposively selected, in order to gain perspectives from adolescents who attend both paediatric-specific and general services.

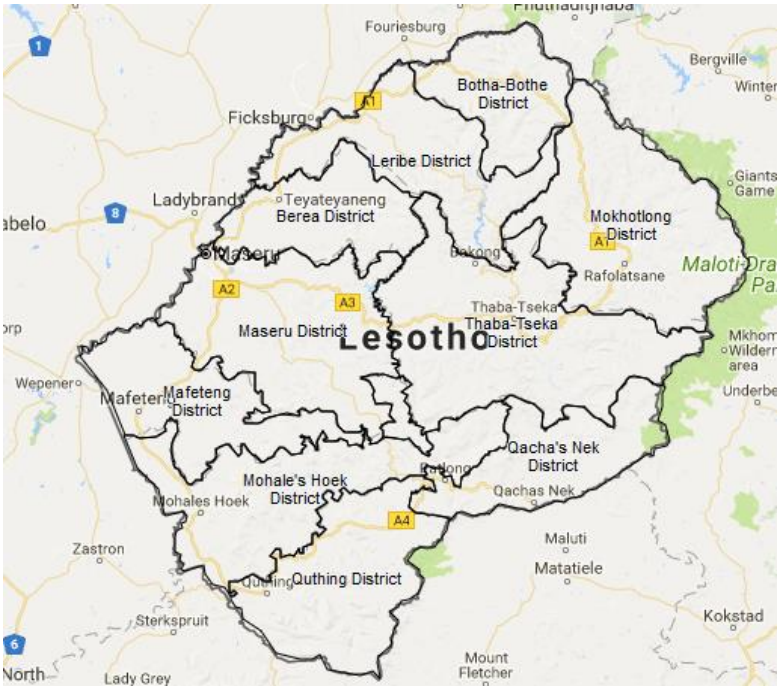

Figure 1.2 Map of Lesotho. Districts of Lesotho with Botha-Bothe District (map copied from DHIS 2 15/7/18)

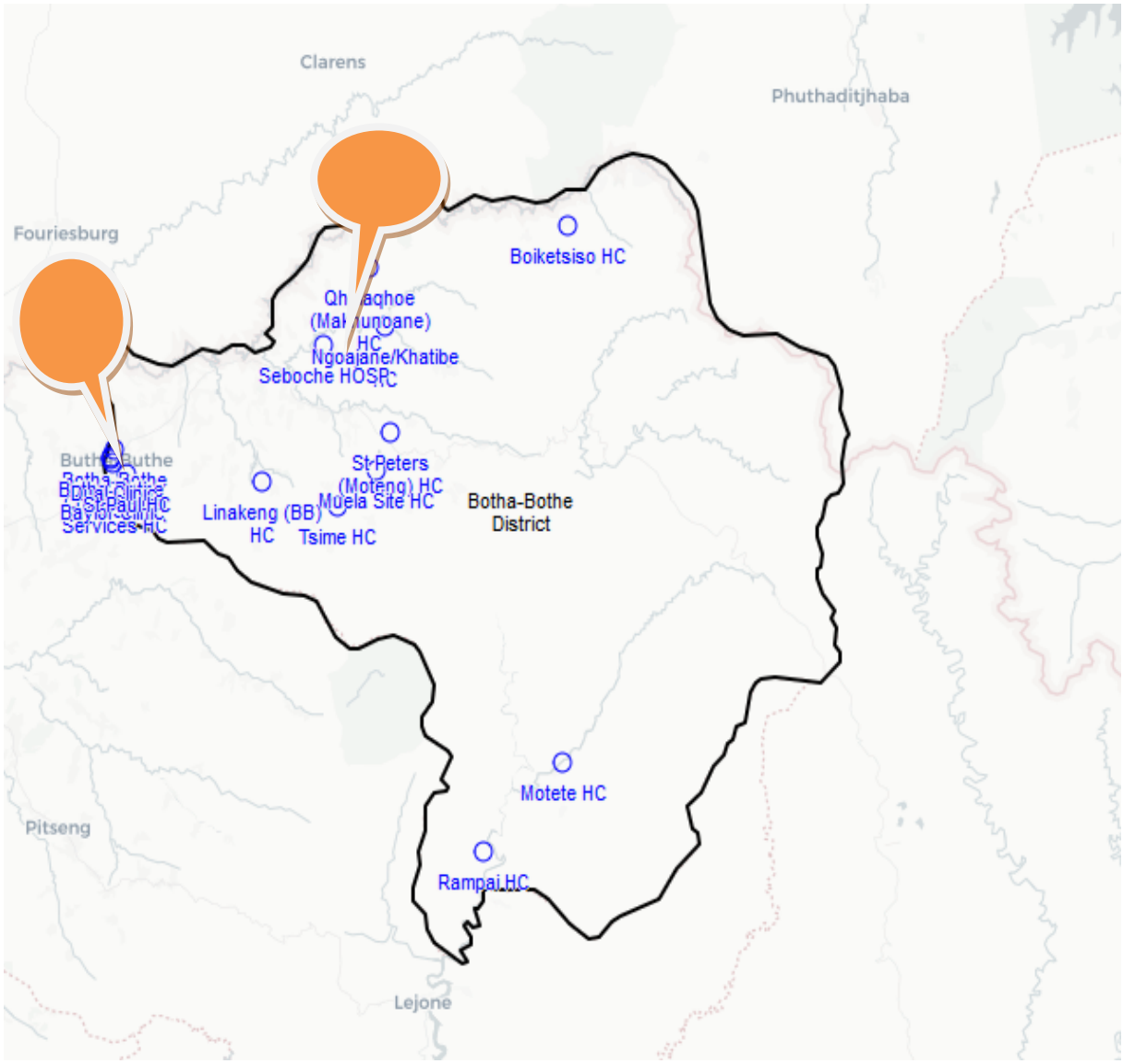

Figure 1.3 Map of Botha-Bothe District with health facilities
Legend HC: Health Centre

Ngoajane Health Facility is the public primary health care facility situated in the peripheries of Botha-Bothe district. An estimated population of 5 040 people access health services from this facility (Lesotho Bureau of Statistics, 2006). The facility is about thirty-five (35) kilometres from the town of Botha-Bothe and it serves the rural community, whereby some people travel approximately five (5) kilometres to access services at the facility. The facility makes provision for the needs of adolescents to some extent, since they have a teen club. At the club teenagers discuss their life experiences, they are taught life skills and the adherence to treatment is enforced. Although the teen club was established a while ago, it is not functional.

Baylor Health Facility is situated in Botha-Bothe. It provides chronic HIV care services to children from age two (2) to twenty (20) years old. Botha-Bothe Hospital is situated in the semi-urban town of the Botha-Bothe district. It serves an estimated population of 16 107 according to Lesotho bureau of statistics of 2006.The facility has a teen club that is fully functional. People accessing services from these health facilities are of low and middle socio-economic status and services are provided free in both facilities, since the Government of Lesotho incurs the expenses.

1.7.3 Population and sampling

The sampling method that was used was purposive sampling whereby the researcher selected certain information-rich participants (Grove, Gray & Burns, 2015:270) to obtain in-depth information. For the purpose of this study, adolescents in the middle (14 to16) and in the late adolescence (17 to 19) stage were sampled. Twelve (12) participants were interviewed.

1.7.4 Data collection tool

A semi-structured interview guide were used; whereby participants were asked open-ended questions with probes (see Appendix 4).

1.7.5 Pilot interview

The first participant interview served as a pilot interview. The purpose of this pilot interview was to assess whether the questions were clear. It was also used to refine the researcher's interview skills. The interview was included in the main study for analysis.

1.7.6 Trustworthiness

Trustworthiness is the process of applying different strategies to ensure that research findings are accurate from the standpoint of the researcher, the participants and the readers of the study (Creswell, 2014:201). The researcher applied principles to ensure accurate findings of the experiences of participants, namely credibility, dependability and confirmability. The principles are discussed in Chapter 3.

1.7.7 Data collection

Data was collected through semi-structured individual interviews. When conducting interviews, the researcher guides the discussion in order to understand participants' experiences through story telling. The researcher poses probing questions for more information (Ritchie, Lewis, Mcnaughton-Nicholl & Ormston, 2014:111). The researcher conducted face to face interviews with the participants attending healthcare services at Ngoajane and Baylor Health facilities, at the time and the place preferred by the participants. The main language that was used in this area is Sesotho, and the researcher is fluent in this language. Data was collected from August to October 2018.

1.7.8 Data analysis

The seven steps suggested by Creswell (2014:187) were utilized during data analysis. The method used to analyse data was thematic analysis.

1.8 ETHICAL CONSIDERATIONS

The researcher applied ethical principles in the study. Approval was obtained from the Health Research Ethics Committee (HREC) from Stellenbosch University before conducting the study (HREC Ref: S18/02/022). Permission was also requested from the Research Coordinating Unit of the Lesotho Ministry of Health, (Ref: ID115-2015). When approvals had been obtained, the researcher wrote a letter, requesting permission from facilities. Copies of the approval are attached as Appendix 1 and 2.

1.8.1 Right to self-determination

The participants were informed about the study. For adolescents under the age of eighteen (18), assent for participation in a research project from the adolescent and parental consent were obtained. The research objectives were expressed verbally and in writing and these were explained in the language (Sesotho) that the participants understood. Consent was requested from the parents of participants under the age of eighteen (18), but nevertheless participants were asked to confirm their willingness (assent) to participate in the study i.e. none were forced to participate in the study. They could choose whether to participate or not.

The Declaration of Helsinki 2013 stipulates that if a potential research participant is incapable of giving informed consent, the researcher must seek informed consent from a legally authorized representative (World Medical Association, 2013:2). However, the participants' opinion should be respected. We anticipated that there may be cases where an adolescent under the age of eighteen (18) do not give permission for the researcher to contact his or her parents to obtain parental consent, due to the fact that their HIV status is not known to the parent. The researcher therefore asked permission from the HREC to waive parental consent in such cases. The researcher did not want to unfairly exclude such participants and she wanted to respect their rights to keep their HIV status confidential.

The waiver of informed consent would only apply in cases where the researcher was certain that the adolescent understood the benefits and the risks associated with participating in the study and provided their assent to participate in the study but did not give the researcher permission to contact their parents. However, there were no participants who did not want their parents or guardians to know about their HIV status and therefore there was no need to waive parental consent. The information about the study was provided in a language and at the language level of the adolescent, to make sure that they understood the benefits and the risks associated with the study. They were also allowed to withdraw from the study at any time if they so wished, without penalty (Grove, Gray & Burns, 2015:101).

1.8.2 Right to confidentiality and anonymity

Personal details were separated from data collected, in order to maintain anonymity and confidentiality. Responses were not linked with individual responses. A Participants rights to privacy was maintained during the data collection and throughout the study. The audio-recordings and transcripts were labelled in such a way that anonymity was maintained.

1.8.3 Right to protection from discomfort and harm

The researcher protected the participants from discomfort and harm. The participants were allowed time to break from the interview when they were fatigued or when the researcher observed restlessness. The option to refer distressed participants was available but there was no need to refer them. Unintended HIV

status disclosure was prevented by asking healthcare workers to identify the participants who are aware of their HIV status.

The participants were offered refreshments during the interviews. Travelling costs for the participants was covered by the researcher. On average, sixteen rand (R16.00) for each participant was given to participants, to cover their travel to the interview place and back home. The participants were informed about the data collection procedure and the devices that were used for data collection. The researcher ensured that the information shared by the participants was not relayed to healthcare workers and that their care was not affected negatively if they shared negative experiences.

1.9 DEFINITIONS

Adolescent-friendly health services means services that are non-restrictive, have easily negotiated access, appealing facilities and support staff who are oriented towards adolescents. Adolescent-friendly health services promote adolescent involvement and provide comprehensive services (Tanner et al., 2014:2).

The physical environment incorporates space, learning and leisure facilities (Tanner et al., 2014:1).

The social environment incorporates healthcare workers who are quick to respond to the needs of the adolescent, clear policies and procedures that do not restrict the provision of health services and community support in the provision of services (Tanner et al., 2014:6).

HIV infection means that HIV is present in the body, as confirmed by the appropriate blood test (Van Dyk, 2012:496).

Adolescence is the developmental stage characterised by physical and psychological changes. The individual is neither a child nor an adult as they range from the ages of ten to nineteen (10 to 19) (WHO, 2012:1). This study focused on adolescents aged fourteen to nineteen (14 to 19).

Experience is defined as the process or the fact of personally observing, encountering, or undergoing something (Dictionary, n.d). Experience is the state of

having been affected by, or the gaining of knowledge through exposure (Dictionary, n.d).

1.10 THE DURATION OF THE STUDY

Ethical approval was obtained on 17 May 2018 from the HREC at Stellenbosch University. Permission from the Ministry of Health Lesotho Research Coordinating Unit was obtained on the 16th June 2018. Data collection was done form 1 August to 30th October 2018; while data analysis was done from 1 August 2019 to 30 October 2019.The final thesis was submitted on 1 December 2019 for examination.

1.11 THE CHAPTERS OUTLINE

Chapter 1: The Foundation of the Study

Chapter 1 provides a background to the study topic and an overview of the research aims objectives, methodology and the layout of the study. In this chapter definition of terms is incorporated.

Chapter 2: The Literature Review

Chapter 2 the literature review discusses the epidemiology of HIV among adolescents and adolescents' developmental stages are described. The experiences of adolescents regarding health services are also discussed.

Chapter 3: The Research Methodology

Chapter 3 describes the research methodology used to explore the experiences of adolescents living with HIV, regarding health services in the Botha-Bothe District in Lesotho.

Chapter 4: The Findings of the Research

In Chapter 4 the findings of the study are discussed and interpreted using themes and sub-sub-themes.

Chapter 5: Discussion, Conclusions and Recommendations

In Chapter 5, synthesized findings are discussed, based on the study objectives. The researcher draws conclusions and provides recommendations based on the evidence.

1.12 SIGNIFICANCE OF THE STUDY

Adolescents should receive services that they need and that meet their expectations (WHO, 2010:37). Moreover, health services should be provided to fulfil the needs of adolescents. A study done by Busza, Besana, Mapunda and Oliveras (2014:1), revealed that adolescents need psychological support. Thus, the present study described and explored adolescents' needs and expectations from healthcare workers and health facilities.

This study explored and described the experiences of adolescents living with HIV, in order to help the primary health care facilities to adjust their service provision to meet the needs and the preferences of adolescents. According to Tanner et al. (2014:2), a lack of access to preventive services such as management of opportunistic infections leads to increased illnesses and death. This is the only study conducted so far in Lesotho on this topic.

1.13 SUMMARY

Adolescents need to access quality and comprehensive healthcare services, so that their needs are addressed. The aim of the study was to explore and describe the experiences of adolescents living with HIV, regarding attending healthcare services in the Botha-Bothe District in Lesotho.

A summary of the preliminary literature review and an overview of the research methodology were depicted. Ethical principles, operational definitions, the duration and the layout of the study were also discussed. Furthermore, data collection methods applicable to the study were briefly discussed. In the next chapter, the literature that supports the research topic will be discussed.

CHAPTER 2

THE LITERATURE REVIEW

2.1 INTRODUCTION

The purpose of the literature review is to note and to examine relevant studies about the topic to be studied. The literature review was done to recognize what is known and not known about the experiences of adolescents living with HIV (ALHIV), regarding attending health services.

The review provides information with recent knowledge on the topic and likewise, contributes to the recognition of gaps in that knowledge (Grove, Gray & Burns, 2015:164).

There are few studies on the experiences of ALHIV when accessing health services in different countries and at different health facilities. A plethora of studies discuss contributing factors to poor adherence to antiretroviral treatment. Few studies were identified that were relevant to this topic and provided guidance for the research purpose.

An initial preliminary literature review was conducted while writing the protocol, followed by an in-depth review after data collection and analysis.

This chapter contains an in-depth literature review. The literature review focused on adolescence as a developmental stage, the effect of HIV on development, adolescent-friendly health care services and adolescents' experiences of health care services.

2.2 SELECTING AND REVIEWING THE LITERATURE

The purpose of the literature review of the literature review was to search for empirical studies related to the study topic. Empirical and non-empirical literature was reviewed. Information was sourced from recent sources, which were not older than ten (10) years. The following databases were searched for information: WHO Library Cataloguing-publication Data, Science Direct, BMC Public Health, PubMed, and SUN library. The following search terms and their Medical Subject Headings (MeSH) terms were used while conducting the literature search: adolescence,

adolescent-friendly services, adolescent development, preferences for health services and experiences of adolescents living with HIV.

The literature review is presented according to the following main sections:

- Adolescence and adolescent development;
- Epidemiology of HIV among adolescents;
- Adolescent-friendly services;
- Adolescent preferences for health services; and
- The experiences of adolescents living with HIV infection.

2.3 ADOLESCENCE AND ADOLESCENT DEVELOPMENT

The term adolescence is defined in this section. Developmental tasks and the influence of HIV on development are discussed.

2.3.1 The definition of adolescence

Adolescence is a time of human growth and development, which occurs after childhood and before adulthood. Adolescence is defined as the age range from ten to nineteen (10 to 19) (WHO, 2012:5). It is the period of preparation for adulthood; a child's transition from dependence on caregivers to a large degree of independence.

Changes in biological processes such as physical, psychological, social interactions and relationship changes take place. It is also a time of risk-taking and it may be characterized by unplanned behaviours and the inability to control oneself (Brittain, Myer, Phillips, Cluver, Zare, Stein & Hoare, 2019:131).

Adolescence is the transitional phase of development whereby adolescents think that they are very important. They have their unreal people (imaginary audience) who they think are watching whatever they are doing. Whatever they do, they do it to impress this imaginary audience. At this phase, there are changes in individual roles (Fleming, 2018:26).

Adolescents try to acquire and find the roles that will be assimilated in adulthood. These roles should also be incorporated into the family, the community, and into culture. At this stage, the adolescent is not yet mature; they are not able to express their feelings like adults, but socially they are expected to be emotionally mature

while, they are not (Curtis, 2015:1). Knowledge of adolescent development empowers people who work with adolescents. In the following section, the developmental tasks of adolescents are described.

2.3.2 Developmental tasks of a healthy adolescent and the influence of HIV on development

Adolescence is an unstable stage in life; there are radical changes that take place in the body. Adolescence starts with a natural process to achieve developmental tasks and to develop a sense of personal identity and it ends when young people accomplish independence.

This stage is marked by vigorous body growth, an increase in the ability to express sexual feelings, new social roles, and growth in thinking. Adolescents at this stage, define their feelings, and their morals and they are striving for self-awareness (Kalombo, 2015:2). Developmental tasks of the healthy adolescent will be explained based on Piaget's cognitive theory and Erickson's developmental stages (McLeod, 2018:5). How HIV can impact on normal adolescent development will be discussed below.

2.3.2.1 Physical development

Adolescence is characterized by quick and tremendous physical growth. There is an increase in height and weight caused by the secretion of growth hormone. The shape of the body changes as there is a change in the collection and the distribution of fat and muscle mass strength increases.

The process of physical growth and mental or emotional development is regulated by the hypothalamic-pituitary-gonadal axis (Ozdemir, Utkualp & Pallos, 2016:717). Secondary sexual characteristics appear, and sex organs are stimulated to produce sex hormones (Ozdemir et al., 2016:718).

2.3.2.1.1 Influences of HIV on physical development

HIV influences physical development which results in stunting, whereby growth in height and weight is impaired. ALHIV may look smaller than their peers (Mwaba, Ngoma, Kusanthan & Menon, 2015:4). Opportunistic infections may cause physical

changes that make them look different from their peers and affect self-image negatively.

Adolescents living with HIV have a delay in the onset of puberty (Armstrong, Lorpenda, Caswell and Kihara,, 2017:10).

2.3.2.2 Cognitive and social development

According to Piaget's cognitive theory, adolescents reach formal operation thought, meaning that they reason based on facts and they can think logically and explore the world around them (Piaget, 1939 in McLeod, 2018:5). They usually question what they have been taught or hear from their parents or from their community. This process is also dependent on the natural abilities and skills of the individual adolescent.

Adolescents increase contact with others outside the family, and peers play a more important role in their lives (Mcleod, 2018:5). Adolescents may fail to differentiate between what is important to them and what is of interest to others (Van Dyk, 2012:203). They also question adult family rules and they claim freedom from their parents (Ozdemir et al., 2016:720).

2.3.2.2.1 The influence of HIV on cognitive development

HIV affects brain development and may cause neurological and development delays, decreased intellectual levels, mental retardation, and learning difficulties. HIV infection is associated with a disorder in attention and memory that is characterized by forgetfulness (Mwaba et al., 2015:3; Mofenson & Cotton, 2013:2; Lowenthal, Kitaka, Chapman, Goldrath & Ferrand, 2014:6).

2.3.2.2.2 The influence of HIV on social development

Adolescents living with HIV encounter difficulties in forming a relationship with their peers. Some adolescents are withdrawn due to internalized stigma and the fear of rejection. The effect of fear lowers self-esteem. Due to deaths caused by HIV, some may not be staying with biological parents and they may feel isolated and lonely (Armstrong *et al.,* 2017:10).

2.3.2.3 Identity development

As stated in Erickson's stages of psychosocial development (Macleod, 2018:5-6), adolescents discover who they are and they clarify their beliefs about their characteristics, roles, goals, interests, values and what makes them unique. They consider their existence as very important. Through this search, they discover possibilities and they form their own identity, based upon discovery (Macleod, 2018:5-6). Adolescents consider themselves not prone to any misfortune and that may lead to indulging in risk-taking actions which put them at risk for getting HIV or transmitting HIV to others. Towards the end of adolescence, they tend to settle in their behaviour and in their thoughts (Ozdemir *et al.,* 2016:721)

2.3.2.3.1 The influence of HIV on identity development

Adolescents living with HIV face challenges about who they can trust with the knowledge of their status. This may lead to mistrust of the world around them. They are not able to identify with peers because they fear that they may get disappointed and that they may feel different or not normal. Denial of one's status can affect how adolescents see and interact with the world around them (Armstrong *et al.,* 2017:11). Interaction with peers affects identity development. Frequent illness and withdrawal from their peers may hinder normal activities and interaction and may result in an inability to develop an identity (Petersen, Bhana, Myeza, Alicea, John, Holst, Mckay & Mellins, 2010:6; Kang, Mellins, Ng, Robinson & Abrams, 2008:231).

2.4 HIV EPIDEMIOLOGY AMONGST ADOLESCENTS

Globally in 2018, an estimated 1.6 million adolescents aged ten to nineteen (10 to 19) were living with HIV (UNICEF, 2019:1). The larger number of ALHIV (1.03 million) is within the ages of fifteen to nineteen (15 to 19) and 770,000 are between ten and fourteen (10 to 14) years old. The regions with the highest numbers of ALHIV are sub-Sahara Africa and Asia. The largest proportion of ALHIV being eighty-nine percent (89%) resides in sub-Sahara Africa (UNICEF, 2019:1).

AIDS-related deaths have increased among adolescents. AIDS is a leading cause of death among adolescents aged ten to nineteen (10-19) in Africa and an estimated 33,000 adolescents died of AIDS-related causes globally in 2018 (UNICEF, 2019:1).

The number of annual AIDS-related deaths among the ages of ten to nineteen (10 to 19) was twenty-three percent (23%) higher in 2018 than in 2002. Adolescents account for about four percent (4%) of all people living with HIV.

The Lesotho Demographic and Health Survey (2014:249) reported an HIV prevalence of five-point four percent (5.4%) among women aged fifteen to nineteen (15 to 19) and four point eight percent (4.8%) in men aged fifteen to nineteen (15 to 19). There is presently a strategic focus to end AIDS amongst adolescents. The objectives are to reduce AIDS-related deaths among adolescents by at least sixty-five percent (65%), to reduce new HIV infections among adolescents by at least seventy-five percent (75%) and to have zero discrimination among adolescents aged ten to nineteen (10 to 19) by 2030 (UNAIDS, 2015:1).

The outcomes of ALHIV are poor when compared to adults living with HIV. Adolescent deaths stemming from HIV continue to rise despite declines in other groups (Gage, Do & Grant, 2017:1). A high loss to follow-up loss to follow-up rate is reported mostly for the age group fifteen to nineteen (15-19) (Armstrong et al., 2018: S19). There may be several reasons for this. Adolescents may not be attending HIV services as directed because they do not want to miss school and they may be less involved in their care because when they come during school time, they do not have enough time to engage with healthcare workers (Zanoni, Sibaya, Cairns & Haberer, 2018:960). Behavioural health risks such as alcohol and substance abuse among adolescents contribute to poor adherence to antiretroviral drugs which leads to poor health outcomes (Davies & Pinto, 2015:2).

There is, therefore, a need for differentiated HIV service delivery that will meet the needs of adolescents. Adolescent-focused interventions should involve health services, the community, and peers (Armstrong et al., 2018: S19). Services provided to adolescents should entail all components of adolescent-friendly health care. Adolescents should be involved in planning the program and in executing the activities (Gage *et al.,* 2017:21).

2.5 ADOLESCENT-FRIENDLY SERVICES

Adolescent-friendly services are services that are easy to reach, they are appealing, and they are delivered in acceptable ways to adolescents, to meet their health needs (WHO, 2012:7).

Considering the health of adolescents, the need for adolescent-friendly services was identified to lessen the load of diseases and to decrease the number of deaths that occur amongst adolescents. Adolescents living with HIV face major barriers to accessing treatment and care programs, and these are usually exacerbated for adolescent girls and adolescent key populations such as transgender people, sex workers and drug users (Davies & Pinto, 2015:1). These adolescents are usually denied HIV services or are incapable to access them, due to age and behaviour related discrimination, gender and socio-economic inequalities. Adolescents living with HIV have distinctive needs due to the changes that they are experiencing, encompassing physical, cognitive and social changes, as well as their life circumstances. Accordingly, adolescents often face challenges with adherence to treatment resulting from treatment fatigue, lack of health literacy, power imbalances with their healthcare provider, pill burden and non-existent social and nutritional support in education settings (UNAIDS, 2014:3).

Adolescents need adherence support and information about their treatment regimens from health service providers and from their communities so that they can feel motivated to take their medication and have the confidence to assume responsibility for their health (UNAIDS, 2014:4; Kidia, Mupambireyi, Cluver, Ndhlovu, Borok & Ferrand, 2014:4). Adolescents face difficulties in access health services on their own. Contributing factors include stigma, the lack of youth-friendly services and parental consent policies. UNAIDS plans to reach HIV treatment targets and adolescents area key population group by reaching 90-90-90 targets by 2020.

This means that ninety percent (90%) of people (adults, children, and adolescents) living with HIV will know their status. Ninety percent (90%) of those diagnosed will be on continual antiretroviral therapy (ART) with a ninety percent (90%) viral suppression rate in those on ART (Davies & Pinto, 2015:2). To reach these targets, health services must become more relevant for adolescents. Adolescent health services should meet adolescent health needs considerately, profitably and include

all adolescents (WHO, 2014:4). Adolescents prefer to be treated with respect and that their confidentiality is protected (WHO, 2012:5). These services should entail the characteristics below.

2.5.1 The characteristics of adolescent-friendly health services

Adolescent-friendly services should entail both the physical and the social environment. The physical environment comprises space, learning and leisure facilities. The walls of health facilities should have drawings and paintings that are attractive to adolescents. Decorating objects and images in the facilities should be adolescent-friendly. Space should be furnished with chairs and tables that allow adolescents to relax. There should be posters, music, and books that are interesting for adolescents (Tanner et al., 2014:1). The physical environment should also be safe (WHO, 2012:31). Services should be adjacent to schools to make them more accessible and they should be linked with youth clubs and schools (Gage et al., 2017:21). Services should also be given after school hours so that adolescents do not miss classes to get services during school hours (Zanoni et al., 2018:961).

The social environment comprises healthcare workers who are reactive to the needs of the adolescent, clear policies and procedures that do not restrict the provision of health services and community support in the provision of services (Tanner et al., 2014:1). The services need to be complete, delivering a necessary package including appropriate prevention, care, treatment and support for adolescents. The point of service delivery should have the equipment, the supplies, and the primary services necessary to deliver the needed health services (WHO, 2012:31).

Adolescent health care services should be delivered by trained and inspired healthcare workers who are technically skilled. Age-relevant health promotion, prevention, treatment, and care should be provided. Adolescents should be given information about services that are accessible. Healthcare workers should know how to communicate with adolescents without being judgemental (WHO, 2010:34).

Adolescents should be allowed time to relate to healthcare workers; to develop a stronger connection. ALHIV should network more often with peers to cheer-up and to support each other (Zanoni et al., 2018:961).

Adolescents should be included in planning their health care services. The WHO published a document entitled; “Making health service adolescent-friendly, developing national quality standards for adolescent-friendly health services”, which indicated that adolescents should be eager and able to obtain the health services that they need (WHO, 2012:31) and to recommend the services to their friends.

2.5.2 The minimum standards for adolescent-friendly services in Lesotho

The Ministry of Health in Lesotho developed national minimum standards and an implementation guide for the provision of adolescent-friendly health services.

The standards are based on key health and development outcomes, which include:

i) the reduction of maternal morbidity and mortality due to pregnancy and childbirth among young people;

ii) the reduction of morbidity and mortality due to unsafe abortions;

iii) the reduction of unintended pregnancies, sexually transmitted infections, and HIV;

iv) the reduction of domestic and sexual violence and ensuring good management of the survivors; and

v) the reduction of accidents and violence-related injuries (Lesotho Ministry of Health, 2006:18).

Therefore, eight (8) quality standards were developed namely that all young people should have access to health services, including those who request an abortion, the intellectually challenged, the physically challenged, drug users, gays and lesbians, sex workers and young adolescents. To achieve the first standard, healthcare workers should be cognisant of policies regarding health care access for young people.

Secondly, information on sexual reproductive services should be given at a suitable time, without considering payment. The third standard is to broaden the use of health services effectively. This will be achieved by starting a youth corner to improve privacy and confidentiality. Youth corners are places that provide services for adolescents. Adolescents can come to these corners to meet with others; learn

about health issues and to share their challenges. Peer educators are deployed in youth corners to share information with other adolescents. The fourth standard indicated that service providers should be equipped with the knowledge and the skills to deal with sexual reproductive health, mental health and domestic and sexual violence. In the fifth standard, the emphasis is on providing enough supplies and equipment to give complete health services. The sixth standard specified that sexual reproductive health services that are given in health facilities and outside health facilities should be accepted by parents and the community. The seventh one advocates for the inclusion of young people in the planning, enaction and evaluation and assessment of services. Lastly, quality assurance systems, information systems, and financial decisions should reinforce the execution of services to young people (Lesotho Ministry of Health, 2006:21-22).

2.5.3 Standards for adolescent-friendly services in South Africa

Standards for adolescent-friendly services are expressed as six objectives in the National Adolescent and Youth Health Youth Health policy (Republic of South Africa 2017).

They are spelled out as follows:

i) commencing, youth-oriented programs and technologies to promote the health and the wellbeing of adolescents;
ii) advance information technology programs to encourage the commitment of adolescents and the youth with the health service; and
iii) expand and build digital channels of education, information, and support, by adopting mobile technologies, creating health information applications, health monitoring tools, and patient feedback mechanisms (Republic of South Africa , 2017:5).

Care for HIV/AIDS, tuberculosis, sexual reproductive health should be integrated, so that adolescents receive all services at one visit. Where this is not practical, referral systems should be strengthened to ensure easy access for adolescents and for the youth to linked services (Republic of South Africa, 2017:7). Adolescent and youth-friendly clinic spaces must endeavour to meet the practical and the psychosocial requirements of their target users, including operating hours that accommodate

learners' timetables, that maintain privacy, and that employ non-judgemental staff. Contraceptive care should include the provision of a range of methods such as the promotion of the use of contraceptives and condoms at the same time (dual protection). Adolescent clinics should prevent, test, and provide treatment for HIV and tuberculosis, retain patients within healthcare services and support better adherence to medicines (Republic of South Africa, 2017:7). Chronic and communicable-disease management and sexual and reproductive health services should be combined. Mobile clinic services should also provide HIV and tuberculosis prevention methods and the treatment of ten to twenty-four (10 to 24) year olds.

Substance abuse and violence should be stopped because they affect the health of adolescents in general. Therefore, post-violence care should be integrated into the complete package of sexual and reproductive health. There should be a focus on the nutrition of the adolescent in general and adolescents should be included in policy development and take part in the implementation of programs (Republic of South Africa, 2017:14).

2.6 ADOLESCENT PREFERENCES FOR HEALTH SERVICES

A study that was conducted in the Netherlands on adolescents living with chronic conditions found that adolescents preferred to be consulted by healthcare workers who are competent, honest, and trustworthy and who attend to their needs. Health workers should not treat them as children and care should be given, according to their age. They also prefer to choose their services and to decide on their care and the services provided to them (Van Staa, Jedeloo & Stege, 2011:295-297).

Furthermore, healthcare workers should communicate well by listening to, paying attention to and to value adolescents who respond to all their questions and attend to the adolescent's needs and the parents' concerns. According to Van Staa *et al.,* (2011:298), adolescents prefer to be given enough time for the consultation and they recommended an appealing waiting room environment and surroundings. Adolescents do not want to wait for a long time before the provision of services.

In South Africa, Adams (2017:51) found that health facilities do not have an appealing environment that can motivate adolescents to come for services. Adolescents living with HIV prefer a private, safe environment to ensure privacy. If

services are provided where privacy cannot be maintained, adherence is likely to be poor (South African HIV Clinicians Society, 2017:36). Adolescents need to interact with friendly and motivated healthcare workers (Adams, 2017:51). Healthcare workers must share health information easily. Healthcare workers should have a welcoming, non-judgemental attitude towards adolescents. Moreover, their HIV status, discussion, and decisions regarding care and treatment should be confidential (WHO, 2013 (a):4).

Adolescents also prefer to be given appropriate information about HIV. Health facilities should be a safe space where they can freely express their emotions and their concerns. Furthermore, healthcare workers should show patience, understanding, acceptance, and knowledge about the choices and the services available to adolescents. According to WHO (2013(a):6), adolescents prefer services that address their needs in a friendly manner. They also require counselling and support services in the context of their HIV status.

WHO (2014:8) stipulated that adolescents prefer to get health care services without their parents' consent, and they need all the services in one place to avoid referral or multiple dates to come back.

2.7 EXPERIENCES OF ADOLESCENTS LIVING WITH THE HIV

This section relates to the experiences of ALHIV and other adolescents of health care services. Few studies have explored the experiences of adolescents living with HIV, especially in the African context.

2.7.1 Social environment

The WHO (2013 (b):14) conducted a survey whereby four hundred and forty-seven (447) ALHIV were recruited from fifty-seven (57) countries, including sub-Sahara African countries. The study revealed that eighty-five percent (85%) of participants aged ten to twenty-four (10 to 24) reported good communication with healthcare workers and they felt free to ask general and HIV related questions. Hornschuh, Laher, Makongoza Tshabalala, Kuijper and Dietrich (2014:427) reported that the majority of adolescents who participated in their study that was conducted in South Africa in Soweto were able to talk freely about sensitive issues such as sex, with health facility staff and they connected easily with service providers, while fifteen

percent (15%) did not communicate well with the healthcare workers. Health facility staff maintains confidentiality during the provision of services, and they are trustworthy. The study also found that healthcare workers tried to follow-up on those who did not come for services at the time appointed (Hornschuh et al., 2014:14).

On the other hand, adolescents mentioned that healthcare workers sometimes fail to realize the reasons why adolescents do not take their medication. They overtly show their dislike of non-adherence behaviour (Hornschuh et al., 2014:427).In the study conducted by Zanoni et al. (2018:961) in KwaZulu-Natal, adolescents expressed that health facility staff does not talk to them in an acceptable way when they do not adhere to appointments. Adolescents felt that they were not allowed to talk about personal problems. They are only given information about HIV and medication. Adolescents also stipulated that it is not easy to adapt to new healthcare workers (Hornschuh et al., 2014:427).

2.7.2 Physical environment of the health facility

In the study by Mburu, Ram, Oxenham, Haamojompa, Lorpenda, and Ferguson (2014:15) in Zambia, adolescents mentioned that it is not easy for them to access health facilities because they are located far from their place of residence. Adolescents stipulated that at the health facilities there should be space where they can spend time with their peers to relax and to get their follow up-treatment.

Educational materials should be available and should be written in a simple language that they can understand. Adolescents' caregivers should also be given educational materials that will assist them in how to handle adolescent issues (Hornschuh *et al.,* 2014:428). According to Crowley (2018:149), adolescents like to have privacy, due to the stigma regarding HIV status that still prevails in health facilities and in communities. The study also found that attending services in an area dedicated to HIV care increased the perception of stigma.

2.7.3 Services

The survey conducted by WHO (2013(b):13) revealed that healthcare services are within reach. Adolescents can access healthcare services without disturbing their usual daily activities. Adolescents mentioned that they do not wait for services for a long time and that those services are provided by trained healthcare workers.

Twenty-six percent (26%) of adolescents who took the survey also expressed that health facility attendance did not disturb their usual activities. However, fifty-six percent (56%) of the participants reported that health facility appointments disturbed their usual activities.

In Zambia, Mburu *et al.,* (2014:15) found that health facility attendance affected adolescents' daily activities. Schedules for health facility visits are not flexible enough to accommodate adolescents' needs. Adolescents mentioned that if services can be scheduled after school, that they will attend those without missing school (WHO, 2013:13). Furthermore, after-school appointments will allow them to interact with health facility staff and improve their participation in their care (Zanoni *et al.,* 2018:559-960). Adams (2017:50) found that adolescents are annoyed by waiting for services for a long time and they lose interest in seeking information from healthcare workers.

2.7.4 Support

In the survey conducted by the WHO, adolescent participants mentioned that healthcare workers supported them by portraying caring attitudes and visiting them at their homes. Health facilities also allowed adolescents to meet with other adolescents living with the HIV infection, to share whatever they encounter in life and to comfort each other (WHO, 2013:15). Mburu *et al.,* (2014:15) explored the experiences of adolescents living with HIV in Zambia and found that adolescents were concerned about stigma in health facilities. Hornschuh *et al.,* (2014:247) found that adolescents find more support at the health facility than at their homes. Other support systems mentioned in the literature include support from peers and support from family members. Peer support may be difficult to obtain, as adolescents are reluctant to tell their friends about their status. Therefore, it is not easy to obtain social support (Zanoni *et al.,* 2018:960). No qualitative studies on the experiences of adolescents accessing services in Lesotho were found.

2.8 SUMMARY

In summary, the literature review provided current information relevant to the topic to be researched. The term adolescence was identified according to the WHO. Global standards and adolescent-friendly health services were discussed. Furthermore, the

experiences of adolescents living with HIV were discussed, based on the information derived from the literature review. There were mixed experiences; some positive and some negative. Although there were positive experiences, there remained challenges concerning the provision of adolescent-friendly services. In the next chapter, the study methodology is discussed.

CHAPTER 3

RESEARCH METHODOLOGY

3.1 INTRODUCTION

The previous chapters provided a background to the study, including a literature review of the experiences of adolescents living with HIV regarding attending healthcare services. This chapter provides a detailed discussion of all the steps of the research process applied in conducting the study and the measures to provide trustworthiness. The research process gives direction for the application of the sequence of actions. Detailed steps of the process can be evaluated and can be repeated to achieve needed results (Grove et al., 2015:38).

3.2 THE AIM

The aim of the study was to explore and describe the experiences of adolescents living with HIV, regarding attending healthcare services in the Botha-Bothe District in Lesotho, in order to make recommendations towards improving adolescent-friendly services.

3.3 THE OBJECTIVES

The study objectives were to:

- Describe the experiences of adolescents living with HIV and about the health facility's physical environment.
- Describe the experiences of adolescents in the social environment and in their interaction with healthcare workers.
- Determine the types of healthcare services utilized by ALHIV.
- Identify adolescents' expectations regarding healthcare services.

3.4 THE STUDY SETTING

The setting is the site used to conduct a study. The setting can be natural or controlled (Grove,et al., 2015:276).

The study was conducted in a natural setting. The researcher did not change the environment. Participants were recruited while attending services at the Ngoajane Health Facility and the Baylor University Health Facility and their routine services were not interrupted by the study. The study setting was discussed in depth in Chapter 1. In this chapter, the researcher will discuss how the services at each of the facilities are organised.

Ngoajane is a small health facility with fewer adolescents compared to Baylor which is larger. At Ngoajane, adolescents are appointed for HIV care and treatment services on a Saturday when they are not going to school. The 'teen club' which was previously conducted was not functional at the time of the study because there was no financial assistance for it. At the teen club, when it used to function actively, adolescents are taught about HIV, the importance of taking medication, side effects from drugs, life skills and they play various games (Jin & Elliot, 2015:107). At the end of the day, adolescents are provided with snacks and transport reimbursement. During the week adolescents come to the facility for laboratory investigations only because laboratories where blood is taken for tests are closed on a Saturday. Adolescents sometimes must come twice a month if they are due for blood tests that month. At the time of study, adolescents came for clinical examination and medication only on Saturdays.

Adolescents attending Baylor Health Facility receive HIV care and treatment services during the week. Adolescents in the age group ten to sixteen (10 to 16) attend a teen club which is held every second Saturday of the month. Adolescents in the age group seventeen to twenty (17 to 20) attend the 'Wise Youth' club which is held on the first Saturday of the month. At both clubs the activities are the same as those mentioned above that are provided at the Ngoajane Health Facility.

At the 'Wise Youth' club the adolescents are guided to transit into healthy adults and to support each other. Jin and Elliot (2015) designed a curriculum named *Adolescent HIV and psychosocial Support: A teen club training manual resource handbook* which is used at the Baylor Health Facility and the Ngoajane Health Facility has now adopted it.

3.5 THE RESEARCH DESIGN

The research design is the plan that explains how the study will be conducted. This plan maximizes control over factors that could impede the study's desired outcome. The plan also guides the selection of the population, the sampling process, the data collection and the analysis (Grove, et al,., 2015:45). Furthermore, the plan depends on what is known and not known about the research problem, the researcher's expertise, the purpose of the study, and the intent to generalize the findings (Grove,et al,., 2015:45). The study employed a descriptive qualitative research design.

3.5.1 Qualitative research

Qualitative research locates the researcher in the world of participants. It enhances the understanding of the phenomenon as the researcher explores the experiences of participants in their natural setting. The researcher interprets the situation according to the meaning that people ascribe to it (Ritchie et al., 2014:15). Grove et al., (2015:67) define qualitative research as an organized plan used to explain experiences and situations in a certain way, from the participants' point of view.

Deeper understanding of the experiences was derived from the analysis of the participants' words. This design was used because the intent of this study was to answer the research question. The researcher wanted to gain a more in-depth understanding of the participants' experiences.

3.5.2 Exploratory descriptive research

The aim of exploratory research is to recognize the real circumstances that the participants are living in or how they feel about the situation. The design was applicable to answer the research question. According to Grove et al., (2015:77), exploratory-descriptive studies are conducted to provide clear and deep information about the situation. Questions asked during the interviews allowed the participants to tell their story and to describe their experiences. Attention was paid to the facts and what the participants said. Although the researcher guided the discussion, there was still room allowed for additional information (Ritchie et al, 2014:110). The researcher aimed to focus on describing the adolescents' experiences of the components of

adolescent-friendly services, namely the physical environment, the social environment and identifying adolescents' expectations regarding health services.

The intention was to use the participants' thoughts for providing information (Grove et al., 2019:74).

3.6 THE POPULATION AND THE SAMPLING

The study population was adolescents living with HIV in the Botha-Bothe district and accessing HIV services. The researcher directly supervises healthcare workers at Ngoajane Health Facility, but with Baylor Health Facility the interaction is minimal, although the District Health Team Management oversees health services in the district. The researcher is not directly involved in patient care and was therefore not known to the participants. At the time of the study, ten (10) participants were attending health services at Ngoajane Health Facility and one hundred and seven (107) at Baylor Health Facility.

Purposive sampling is the appropriate sampling method to gain insight and to obtain an in-depth understanding of a complex experience (Grove et al., 2015:270). For the purpose of this study, adolescents in the middle fourteen to sixteen (14 to 16) stage and the late adolescence at the seventeen to nineteen (17 to 19) stage were sampled. This age group was chosen because they are more likely to access health care services alone and they can articulate their feelings and their experiences. Furthermore, care was taken to include both males and females.

The aim was to identify experiences that cut across age and gender groups (Ritchie et al., 2014:79). The researcher aimed to ensure that adolescents from the middle and the late adolescent stage were well represented, as well as males and females. The age groups were well represented, but the researcher recruited fewer females as compared to males.

Challenges regarding recruitment are further elaborated on in Section 3.7. Ten (10) males and two (2) females were interviewed for the study, which included six (6) males and one (1) female in the age group fourteen to sixteen (14 to 16) and four (4) males and one (1) female in the age group seventeen and nineteen (17 to 19). The pilot interview was conducted with a male who was sixteen (16) years old. All the participants were Sesotho-speaking as it is the local language in the region. The

sample size in this study was determined by data saturation. Data saturation occurs when additional sampling provides no new information (Grove et al., 2015:274). Saunders, Sim, Kingstone, Baker, Waterfield, Bartlam, Burroughs and Jinks (2017:1897) define data saturation as previously mentioned information being repeated.

Data saturation was achieved when interviewing the tenth participant, but the researcher decided to continue with two (2) more interviews. The two (2) participants did not regularly attend health care appointments and the researcher thought that they might have different experiences. However, no new information emerged.

3.6.1 Inclusion criteria

Inclusion sampling criteria are characteristics that the subject or the element must possess to be part of the target population (Grove et al., 2015:251).

- The adolescents must be between the ages of fourteen and nineteen (14 and 19).
- The adolescents must be attending healthcare services at Baylor or Ngoajane health facilities.
- The adolescents should have knowledge of their HIV status.

3.6.2 Exclusion criteria

These are the characteristics that can cause an individual to be excluded from the target population. The initial exclusion criterion was adolescents who were not able to participate meaningfully in an interview, due to physical or cognitive challenges. However, no one needed to be excluded from the study.

3.7 GAINING ACCESS TO THE STUDY POPULATION

The researcher visited the facilities and she explained the purpose of the study. The researcher requested the nurses to assist in identifying participants who met the inclusion criteria.

The nurses at Ngoajane Health Facility suggested that the researcher should visit the health facility on caregivers' day. On that day all adolescents were expected to

be escorted by their parents or by their caregivers. Nurses identified the participants who met the inclusion criteria during the caregivers' day.

The researcher approached five (5) participants. Two (2) of these participants were not between the ages of fourteen and nineteen (14 and 19) and they could therefore not be included in the study.

The researcher met with the caregivers who were mostly grandmothers. The researcher talked to them individually to explain the aim and the objectives of the study thoroughly in Sesotho.

The caregivers signed written consent for their adolescents to take part in the study and adolescents below eighteen (18) years old signed assent forms. One (1) prospective participant did not come for an interview because he had gone to Circumcision School.

At Baylor Health Facility, the researcher was advised to come during the teen and the Wise Youth club events. The doctor and the nurses identified the participants who met the inclusion criteria and they referred them to the researcher.

The researcher approached thirteen (13) adolescents and spoke to them individually. The aim and the objectives of the study were explained thoroughly in Sesotho.

Two (2) girls declined as they were not willing to be part of the study. One (1) male agreed to take part, but on the day of the interview he did not show up. His mother came to collect treatment for him, and she reported that her son was no longer willing to participate.

One (1) participant who was approached told the researcher that he was sixteen (16) years old although he was nineteen (19) – indicating that he would need a guardian's consent. That denoted that he was not willing to participate although he did not voice that and did not participate. Those who were above eighteen (18) years old signed the written consent forms.

Some of the adolescents attending Baylor Health Facility did not attend clubs. The researcher visited the facility in order to access them during their appointments. For those who attended their appointments alone, the researcher contacted the caregivers to explain the purpose of the study and she emphasized confidentiality.

The researcher gave the adolescents consent forms to take home to be signed by their parents or by their caregivers. Their parents and their caregivers signed written consent and the adolescents under the age of eighteen (18) signed the assent form. One (1) participant was staying at a foster home; therefore, the researcher obtained consent from the legal guardian at the foster home.

Table 3.1 Population and Sample

	Ngoajane	Baylor
Population	10	107(DHIS 2) District health information system version 2
Participants approached	5	13
Participants not meeting inclusion criteria or declined	2	3
Participants who agreed to participate	3	10
Participants interviewed	2 (including the pilot)	10

It was not easy to access adolescents who met the inclusion criteria for the study because they were not attending health services as expected or they were reluctant to participate. This can be seen in the discrepancy between the numbers of adolescents who registered for HIV care compared to the number who were approached by the researcher. Some participants, after agreeing to participate, did not attend the interviews at the appointed times and they postponed the appointment. However, they eventually participated. All the participants knew about their HIV status and all of them were infected, through mother-to-child transmission, according to their history.

3.8 INTERVIEW GUIDE

Semi-structured interviews were conducted; whereby participants were asked open-ended questions with probes (see Appendix 4). This open-ended interview assisted the researcher to get more information from the participants (Grove et al., 2015:83). A small number of questions were asked, to get views and opinions from the participants (Creswell, 2014:190). The questions were based on the research objectives. An example of a question is: “Can you tell me more about your feelings regarding this facility’s physical environment?” Probing questions such as: “How

does the environment look?" were also used. The comfort of the participants was considered. The researcher observed that the adolescents did not want to stay long for the interview. The researcher tried to gain in-depth information by reflecting, summarising and asking probing questions. The participants were interviewed in Sesotho because it was the language that they were comfortable with when expressing themselves.

Each interview started with a few demographic questions: gender, age, the name of the health facility and how long the participant had been accessing services from the facility. Participants who became silent during the interview were allowed some moments to reflect. That moment also allowed the researcher to observe body language such as being unsure. At other times, participants became silent because they did not understand a question; and then the researcher had to clarify the question and provide examples.

3.9 THE PILOT INTERVIEW

The researcher was trained on how to conduct interviews and she conducted one interview with a participant who met the inclusion criteria for the main study. Data obtained from the pilot interview was included in the main study because the researcher wanted the voice of the participant to be heard. The purpose of this pilot interview was to assess whether the questions were clear enough. The interview was conducted in Sesotho and then transcribed into English. The study supervisor did not assess the process. She only assessed the transcript. The researcher asked a peer to review the Sesotho interviews and to check the English translation with cultural comments and explanations. She is a Ph.D. qualified nurse educator in one of the nursing schools. The transcribed interview was sent to the supervisor who provided comments; for example, that the researcher should avoid leading questions.

3.10 DATA COLLECTION

Following approval of the proposal by the Health Research Ethics Committee of Stellenbosch University (HREC Ref: S18/02/022) and the Research Coordinating Unit of the Ministry of Health Lesotho (Ref: ID115-2015), the researcher wrote a letter to the Baylor and the Ngoajane health facilities to request permission to

conduct the study. Authorization to conduct the study in the district was also given by the district Medical officer in charge of all health facilities. Permission was obtained from the associate director of Baylor Health Facility and the Nurse in charge of Ngoajane Health Facility. The interviews were conducted over a period of three (3) months - from August 2018 to October 2018. Data was collected through semi-structured individual interviews (Ritchie et al., 2014:180).

The researcher used interviews because she was interested in getting a clear interpretation and an understanding of the experiences of the participants. The researcher conducted face to face interviews with the participants. At Baylor Health Facility, most of the participants were interviewed after their appointments. For three (3) of the participants; an appropriate day was arranged for the interview, as it suited them. The participants were interviewed in a place away from the facility.

At Ngoajane Health Facility, participants attend services every month and the researcher visited the facility over a period of two (2) months, to conduct interviews. The interviews were conducted in a private room at the facility. The main language that is used in this area is Sesotho, and the researcher is fluent in this language. All interviews were conducted in Sesotho. At the beginning of the interview, the researcher asked more general questions to urge the participants to relax. General questions promoted the interaction between the participants and the researcher. However, the participants appeared very tense at the beginning of the interviews.

The researcher anticipated that it was due to the age difference and the knowledge that the researcher is a nurse. The researcher, therefore, employed skills to assist them to relax and the participants appeared to relax, and information was more forthcoming, as the interview continued. Most of the adolescents were able to articulate their feelings although they preferred the interview not being too long. The duration of the interviews was twenty (20) to forty (40) minutes. The researcher felt that she connected better with males compared with females. This may be because the researcher has a male adolescent in the family, and she is acquainted with their language and their behaviour.

The researcher was aware of the uneasiness with females and therefore spent time with the female adolescents attending the clinic and at the beginning of the interview to acquaint herself with their behaviour and their language. The females seemed

less relaxed although they did not decide to leave the interview and they answered all the questions. The audio-recorded interviews were conducted in a private room, in order to provide privacy and confidentiality. The researcher observed how the interview affected the participants' emotions because there was provision made for referral if they were affected emotionally. None of the participants needed to be referred for counselling. The researcher adhered to ethical principles as discussed in Chapter 1.

3.11 DATA ANALYSIS

The seven steps suggested described by Creswell (2014:187) were utilized during data analysis.

3.11.1 Step one: Organize and prepare the data for analysis

The audio recorded interviews allowed the researcher to listen to the data several times and to immerse herself in the data. The audio-recorded interviews were transcribed into English, and then the transcribed interviews were given to a peer to review and to check the English translation with cultural comments and explanations, as described in section 3.9. This included explanations of cultural idioms or words that have a specific meaning in the culture. Pauses and body language were then added (Creswell, 2014:196-200).

3.11.2 Step two: Reading and looking at all the data

The researcher read and looked at all the data. By so doing the researcher recognized the experiences of adolescents living with HIV attending services at health facilities. The researcher tried to depict the meaning out of the data collected.

3.11.3 Step three: Coding of all data

The sentences were divided and grouped according to their meaning and codes were developed (Creswell, 2014:196-200). Codes development was based on the study objectives (Creswell, 2014:196-200). First, the researcher labelled sentences using the actual language of the participants (in vivo coding). One example of a vivo coding was 'talk nicely'. The researcher then read the data repeatedly, the words and the phrases which expressed the feelings of the participants or certain processes were identified. The researcher arranged the codes into categories, based

on how they connected to each other (Theron, 2015:5). For example, all codes such as ‘talk nicely’, age-appropriate language, reprimanding, etc.., were grouped under the category ‘communication’.

3.11.4 Step four: Using the coding process to generate a description

Detailed information about participants and events in the setting was provided; for example, how adolescent services were organized in each of the health care facilities. Coding was used to generate categories which were organized to generate sub-themes and themes. For example, the categories of communication, trust and caring were grouped under the sub-theme of relationship with the health care worker, which further fitted under the theme of the social environment of the health facility. Themes appeared as major findings.

The researcher arranged the categories from the bottom up, patterning the data in units of information until comprehensive themes were formulated. The researcher then looked back from the themes, to identify whether more evidence was needed to support the themes. The supervisor assisted with this process.

The researcher continued to understand the meaning that participants derived from the situation. Themes were used as headings in the findings section. Themes displayed various ideas from participants and were supported by verbatim quotations.

3.11.5 Step five: Represent themes in the qualitative narrative

Themes were generated from major findings. The themes were presented in a qualitative narrative in Chapter 4, with supporting verbatim quotes (Creswell, 2014:200).

3.11.6 Step six: Interpretation of the data

The researcher described lessons learned from the data collected, based on her personal interpretation and she compared the findings with information gleaned from the literature (Creswell, 2014:196-200). The discussion of the findings and the literature is presented in Chapter 5. Recommendations are made based on the study findings.

3.11.7 Step seven: Validating the accuracy of the information

The researcher ensured that the findings are an accurate representation of the participants' experiences. The researcher provided a comprehensive description of the study setting, and she spent a long time in the field to acquaint herself with the participants. Validation of the data was done through the application of the strategies as discussed in the paragraphs below.

3.12 TRUSTWORTHINESS

Trustworthiness is the process of applying different strategies to ensure that research findings are accurate, from the standpoint of the researcher, the participants and the readers of the study (Creswell, 2014:201). The researcher conducted a preliminary visit to the study site to familiarize herself with the area and the participants, where possible.

The researcher went to the facilities several times to recruit participants. The participants were allowed enough opportunity to portray their experiences. The participants' experiences were compared, and conclusions were drawn from similar experiences.

Data accuracy was checked by continuously using reflective summaries during the interviews, to ask participants if the researcher understood them correctly or whether they would like to change anything that they had said. The analysis was carried out systematically and comprehensively. The interpretation was supported by the evidence. The four (4) principles to enhance trustworthiness are discussed below.

3.12.1 Dependability

The transcripts were checked to make sure that they did not contain obvious mistakes made during transcription. The researcher also made sure that the codes were specific to avoid too general meanings. All the steps and the decisions taken during data analysis were recorded (Grove, et al., 2015:392). The supervisor monitored the data collection and the analysis processes, whereupon the researcher documented details (Ritchie et al., 2014:276).

3.12.2 Confirmability

The supervisor confirmed the findings of the study and she commented on them. The researcher kept an audit trail for review by the supervisor (Grove,et al., 2015:392). The supervisor reviewed the audit trail to report whether the researcher's conclusions were logical.

3.12.3 Credibility

To ensure the accuracy of the findings, each person approached was given the opportunity to refuse to participate, to ensure that data collection sessions involved only those who were genuinely willing to take part and who were prepared to offer data freely. The researcher had an in-depth discussion with the participants during the interview (Polit & Beck, 2014:77). During the interview, the researcher rephrased, and she summarized the responses of the participant, in order to understand the experiences of the participant and the meaning that they held. The supervisor reviewed the project and she gave feedback to the researcher. The researcher recorded ideas for each data collection session and the patterns appearing in the data collection, through reflective journaling. The researcher recognized ideas formed before conducting the research throughout the research process. Journaling enabled active learning from the experiences of the adolescents living with HIV attending health services (Vicary, Young & Hick, 2016:7). The researcher produced results that reflect the views of the participants (Grove,et al., 2015:392).

3.12.4 Transferability

The researcher provided a rich and thick description of the study setting and the participants' narratives. The data analysis steps were explained thoroughly (Connelly, 2016:435). The findings of the study may not be generalizable but should be applicable in other settings, with similar participants (Nowell, Norris, White & Moules, 2017:3). The researcher spent considerable time reading and reflecting on data, in order to produce the applicable results (Grove, et al., 2015:89).

3.13 SUMMARY

Qualitative research is interpretive, humanistic and naturalistic as it is concerned with understanding the meaning of social interaction as described by those involved

(Grove et al., 2015:20). The aim of the study was to describe the experiences of adolescents living with HIV regarding attending health services in Botha-Bothe District in Lesotho. Inclusion and exclusion criteria were mentioned. Semi-structured interviews were conducted. This chapter discussed the research design and the processes used during sampling. Data analysis was performed, using the steps described by Creswell, 2014:187). The steps that were taken to ensure the trustworthiness of the data collection process were discussed. The study findings are presented in the next chapter.

CHAPTER 4

FINDINGS

4.1 INTRODUCTION

The findings of the research are presented and discussed in this chapter. The discussion is prepared according to the themes and the sub-themes that were identified through the analysis of the data collected, to describe the experiences of the adolescents living with HIV while attending health services in the Botha-Bothe District. The participant quotes are used throughout to substantiate the interpretation of the researcher.

4.2 SECTION A: DEMOGRAPHICAL DATA

The demographic profile of the participants was considered as it provides a background of the characteristics of the participants. Two (2) participants were female and ten (10) were males. The demographic data that was collected is summarised in Table 4.1 below.

Table 4.1: The characteristics and the number of participants

Age	Gender	Number
14 years	1 male 1 female	2
15 years	2 males	2
16 years	3 males	3
18 years	2 males 1 female	3
19 years	2 males	2

4.3 SECTION B: THEMES AND SUBTHEMES

In this section the findings are presented in themes and sub-themes (Table 4.2). Five (5) themes were identified:

1) The social environment of the health care facility;
2) The physical environment of the health care facility;
3) Services;
4) Support; and
5) The expectations regarding healthcare services.

The study findings emanated from these five (5) themes.

Table 4.2: Themes and sub-themes

Themes	Sub-themes
Social environment of health care facility	Relationship with health care workers Confidentiality
Physical environment of the health care facility	Spaces for entertainment and to relax Health facility surroundings Availability of educational materials
Services	Accessible services Timing of service provision
Support	Family involvement Support from friends Community support
Expectations regarding health care services	Health care services Entertainment

4.3.1 Theme 1: The social environment of the health care facility

Participants voiced issues pertaining to the clinic environment which are discussed in two themes. These themes were identified as the social environment of the health care facility and the physical environment of the health care facility. According to the WHO (2010:37), the social environment of a facility entails two components, namely, health care workers and policies guiding service provision. In this study, the sub-themes related to the social environment, being the relationship concerning healthcare workers and confidentiality. The WHO (2010:37) states that healthcare workers providing services to adolescents should demonstrate good interpersonal

and communication skills. They should be easy to connect with, allocate enough time for their clients, act in the paramount interest of their clients, and value confidentiality.

4.3.1.1 Relationship with healthcare workers

The communication between participants and healthcare workers was challenging. It seemed that it was difficult to communicate effectively because of the generation gap and the participant's adolescent stage of development. Despite this, certain healthcare workers dealt with adolescents in a polite manner and they encouraged them throughout their tenure. Participants mentioned that healthcare workers generally communicated with them in a respectful manner.

> *"They talk to us freely that's what I like about them and us like teenagers they are able to tell us about life and how it is.*" [Participant 4 –18years old].

The healthcare workers appeared to demonstrate practices that hindered good communication. They did not address issues such as missing appointments without emotion, they blatantly communicated their disapproval of an adolescents' behaviour.

The healthcare workers also reprimanded adolescents when they had not taken their medication appropriately. The participants stipulated that certain healthcare workers communicated with them in the same manner as their parents did at home. For example, the healthcare workers do not create the time to understand why they had not come for appointments or taken their medication as scheduled.

> *"Hmk they talk like mothers, they reprimand us."* [Participant 8-14 years old].

> *"They reprimand us so much.*" [Participant 3 – 18 years old]

The lack of adolescent-centred communication had several consequences. Some of the adolescents mentioned that when they are reprimanded, they experience feelings of hurt, which results in them not taking their medication appropriately or avoiding scheduled appointments at the facility.

The healthcare workers did not use words which the adolescents understand when giving information. It further appeared that the healthcare workers did not always employ an age appropriate approach to communication. One of the participants stipulated that he felt threatened by the information given by the healthcare workers; for example, that the medication would harm him if it is not taken appropriately. Such scary information remained in the adolescent's mind and contributed to him missing appointments.

> *"Most of the time they are saying medication will harm me if I do not take them appropriately, if I skip days, so I should not repeat that. I get scared, then after that I become okay. Sometimes I leave the facility still scared."* [Participant 9 – 16 years old].

Adolescents found it challenging to form relationships and to build trust with the healthcare workers. The healthcare workers are rotated, or they are often transferred, thus imposing challenges such as putting their trust inconstantly changing care workers. Participants said that the rotation of healthcare workers affected them negatively because they become familiar with and open to certain people, but when those people leave, they must adjust to new healthcare workers.

> *"Healthcare workers accept us and we have accepted that they offer us services but the fact is when they keep on changing we take time to relate with them some of them, because we were used to the previous ones, however they offer us services in a relaxed atmosphere*." [Participant 4 – 18 years old].

The generation gap between the healthcare workers and the adolescents made it challenging for the adolescents to express their feelings. The adolescents reported that they did not feel free to voice their opinion to healthcare workers because they are adults like their parents. The adolescents are also afraid of the healthcare workers because they do not communicate openly and in a relaxed manner with them when they come for services.

It also appeared that healthcare workers showed a lack of interest in communicating with adolescents. Participants expressed that most of the healthcare workers spent a lot of time on their personal cell phones rather than talking to them. Furthermore,

participants stated that they prefer healthcare workers who talk and sometimes play with them when they come for services.

> *"They do not chat with us; they are only busy with their phones."* [Participant 8 – 14 years old].

Although healthcare workers did not consistently practise effective communication, participants related experiences where the healthcare workers were understanding and supportive. Some of the healthcare workers were able to recognise when the adolescents have challenges pertaining to their care and their treatment. They were able to intervene when the need arose, to counsel and to refer them to other services for intervention beyond their capacity. Participants had a positive experience of these caring behaviours.

> *"They treat me as their children, because by the time I was not taking medication, they discussed among themselves and one of them took me to her home and assisted me to take my drugs until I was sharp."* [Participant 3 – 18 years old].

> *"I voiced out my opinion while I was staying with my grandmother and my grandmother expelled me; they took initiative of finding a place for me to stay."* [Participant 5 – 15 years old].

Good communication skills, trust and caring behaviours are important in building relationships between the healthcare workers and the adolescents. Meaningful relationships are a key aspect of the social environment of a health facility.

4.3.1.2 Confidentiality

Confidentiality is one of the ethical principles in health care services. Healthcare workers must keep all clients' personal matters confidential and they should cultivate this essential skill in their practice. Confidentiality should go hand in hand with privacy; there should be privacy when providing services to adolescents. At both clinics where the study was conducted, services were provided in rooms where privacy is paramount.

The challenge that the adolescents mentioned was that one healthcare facility is not fenced in such a way that other people in the community cannot see what is

happening around the facility. Adolescents preferred not to be seen when they attended services. This may be due to prevailing stigma within communities.

> *"I would like to see the facility fenced in such a way that no people see us when we come for drugs.*" [Participant 2 – 19 years].

The adolescents expressed that they want their HIV status and information to be known by the healthcare workers who they trusted. One of the participants was concerned that the healthcare workers would share his information with other people in the community. However, he later realised that his HIV status had remained confidential.

> *"I was not comfortable to come to the facility because I knew people working at the facility and they knew me, so I thought they will talk about my status all over. But they have not; that was my fear; but so far they are still okay."* [Participant 2 – 19 years old].

There was a concern about having separate services for HIV positive children; participants felt that clinic services should not be dedicated only for them but rather integrated. One participant expressed his feeling that they should be treated like normal children who are HIV-negative.

> *"I would like to get services like other children, so that we do not complain… I do not know how to explain it."* [Participant 1 – 18 years old].

Confidentiality and privacy were concerns for some adolescents. Adolescents are sensitive due to prevailing HIV stigma in communities.

4.3.2 Theme 2: The physical environment of the health care facility

The physical environment of a health facility entails the structure, the surroundings and the materials that provide information to adolescents. Health facilities should be located where they easily be reached and they should be attractive and clean (WHO, 2012:42). Three sub-themes, namely, spaces for entertainment and to relax, health facility surroundings and the availability of educational materials are described below.

4.3.2.1 Spaces for entertainment and to relax

The facilities do not have spaces to relax. Some of the adolescents were not aware whether such spaces existed in the facility or not. The facilities are built in such a way that there are only rooms for counselling and consultations. At the one facility, health care workers provide dedicated services to adolescents living with HIV, while at the other facility, adolescent care is integrated with other services. There are no spaces or facilities for entertainment. Participants reported that they were only entertained at the Wise Youth and teen clubs where they played various games. Entertainment activities occur outside the buildings when adolescents come to the clubs on weekends. There are no indoor entertainment activities or computers for the adolescents to use at the facility, therefore, the adolescents are not able to play computer games. Music is also not played at the facility during the week, although it is played during club events.

> *"Entertainment is done when we have come for teen club every month is then that there is music playing and have different games."* [Participant 2– 18 years old].

One participant expressed his feelings that entertainment facilities are not necessary when they attend services during the week because they can only spend a short time at the clinic to collect medication. However, the same adolescent wished that there could be games and access to the internet when they come for services.

> *"When we have come to collect medication there is no such space because at school, we request permission to come to the facility, so the expectation is that we should be given services then go back to school."* [Participant 1 – 18years old].

> *"Adolescents like current things, I would like that we should be helped with the internet and technology, there are some English words that we do not know their meaning, so you find that we do not have data some of us, but we have to get the meaning. I would like to access the internet."* [Participant 1 – 18years old].

Health care facilities did not have dedicated spaces to relax and spaces for entertainment for adolescents.

4.3.2.2 Health facility surroundings

The adolescents were satisfied with the surroundings of the health facilities. Surroundings referred to the building, the garden, and the outside area. The adolescents viewed the surroundings of their facilities as clean and attractive to them. They also felt it signified that the health care workers respected their place of work.

> *"I am attracted to a clean environment where dustbins are emptied and there is no pollution. Clean environment to me signify that people working in a clean environment respect and care for the place where they are working."* [Participant 1 – 18 years old].

Adolescents had a high regard for the cleanliness of the facilities. It may be due to a health care facility being associated with health and wellbeing.

4.3.2.3 The availability of educational materials

In the facilities there are no educational materials such as pamphlets or books written in a simple language for adolescents to read and understand. There are also no posters against the walls. They rely on the information that they are given by the healthcare workers. The healthcare workers use guidelines and other materials to get the information that they share with the adolescents. The programme does not have pamphlets or information that are given to the adolescents.

> *"There are no educational materials… When we are taught, we sit down; someone stands in front of us and teaches us about the importance of taking medication."* [Participant 7 – 16 years old].

The adolescents expressed that there are no books, pamphlets, or picture books in their facility. None of the participants mentioned the availability of posters as information was mostly shared during health education sessions by the health care workers.

4.3.3 Theme 3: Services

Health services should address physical, social and psychological health. When offering services, adolescents' developmental needs should be considered, to

facilitate the provision of a complete package of health care. A complete package of health care entails prevention services such as provision of contraceptives to prevent unplanned pregnancy, curative services for other diseases and rehabilitative services such as physiotherapy (UNFPA, 2014:1). Two sub-sub-themes emerged on services provided by the facilities which contribute to attendance and utilization.

4.3.3.1 Accessible services

Adolescents do not get a complete package of services at the health facilities. Facilities mainly offer services pertaining to HIV management. All the participants stipulated that the services that they access from the facilities were for care and treatment of the HIV infection. Counselling is provided as part of the HIV care and treatment package.

The adolescents mentioned that they receive curative services when they have symptoms such as a cough. Sexual reproductive services are not provided as a package in health facilities. The package entails universal access to accurate sexual and reproductive health information, safe and affordable contraceptive methods, sensitive counselling, quality obstetric and antenatal care for all pregnant women and the prevention and the management of sexually transmitted infections (UNFPA, 2014:1). Preventive services that are provided at the facilities are contraceptive services, although most of the participants are not conversant with them.

> *"They draw blood to look for viral load, CD4 count, sometimes they check temperature, and sometimes I just come to collect medication only."* [Participant 11 – 18 years old].

Only two participants remembered being taught about contraceptive services, although they had not yet accessed such services. Preventive services were not mentioned by most of the participants. Most of the participants could not verbalise the other types of care that are accessible in the facilities.

A complete package of services is not provided at the entry point to health care services. HIV care and treatment seem to be the priority services provided.

4.3.3.2 The timing of services provision

Adolescents are appointed to come for services on certain days. The frequency and the timing of the attendance is determined by the healthcare workers. In general, the times and the days that are allocated for service delivery are conducive to some of the adolescents.

> *"I still like the way they* [services] *are provided."* [Participant 10 – 15 years old].

However, some of the adolescents stated that they do not want to wait a long time for services at the facility. They expressed that when they come for services, that they should be able to access those in a reasonable amount of time. They also stipulated that since they come for services during school time, they should be given services quickly, so that they can go back to school.

Services in one of the facilities are provided from Monday to Friday. The adolescents are concerned about missing some of the classes when they attended services during the week. This poses challenges for the adolescents to attend as expected. It seems that appointment days are not easily negotiated or flexible; because one adolescent said that she was told that she should come on her appointed day, not any other day. Adolescents feel that they are compelled to disclose their status to their teachers, even if they are not ready yet to do so, when they must attend appointments during school time. The participants also expressed concern about the fear of discrimination that is associated with HIV stigma.

> *"During the week I do not feel comfortable. There are some teachers who do not understand that I request pass out, they ask me where am I going, so I tell them I am supposed to come for check-up, you will find them being surprised, while others do understand that I come for check-up for HIV infection. Sometimes other teachers might ask you what check-up you are going for. Then you must explain. I became hurt at that time, and then later I recover."* [Participant 11 – 18 years old].

Some of the adolescents said that they wished that the timing of service delivery was discussed with them. They expressed that they have a preferred time to come for services. One of the participants expressed that it was not fair for them to come to

the facility frequently. Moreover, the adolescents revealed that the healthcare workers did not explain the reason thoroughly, for coming to the health facility frequently. Due to that lack of collaboration in planning of an adolescents' care, some of them decided not to attend as arranged. One of the participants mentioned that special appointments should be based on their adherence to treatment.

> *"At our time, we should not be given services at school time; during school holidays we should be supplied with a lot of drugs although there are other children who are not taking their drugs; those who are cheating, who do not accept their status. According to me I would like to be given drugs based on how well I am taking them and be given time to come to the facility."* [Participant 1 – 18 years old].

Adolescents were not given an opportunity to participate in or take control of their care and their lives. Health services are not fully tailored to the needs of adolescents to minimize negative reactions towards services. They did not have free choice of available services to promote self-worth.

4.3.4 Theme 4: Support

Support was identified as a contributing factor that affected an adolescents' attendance for health services. Support is giving encouragement to an individual to carry on with any situation or condition that he or she is in (Cambridge Dictionary, s.v. "support"). This will be discussed under three sub-sub-themes: family involvement, support from friends, and community support.

4.3.4.1 Family involvement

Family participation in the provision of health care services promotes and sustains the social and the emotional wellbeing of the individual. Family are people who someone can open their heart to and trust. Family members also provide support and they feel affection for each other (Mondal, n.d.). Family members seemed to be minimally involved in the care and the treatment of adolescents. Most of the participants were staying with their grandparents, who appeared to be overwhelmed by their children's death and the resultant illness of their grandchildren. It appeared as if grandmothers expected the adolescents to attend services on their own, because the grandmothers are older. Sometimes, adolescents forgot to take their

medication because there was no one to remind them. One participant expressed that his grandmother had said that he was now old enough to be responsible for his care. The attitudes of caregivers towards medication and health care also negatively influenced adolescents. One participant stipulated that his grandmother did not want him to take ARVs and she insisted that he should rather take herbal drugs.

> *"I started treatment in 2010, my grandmother was not encouraging me to come for treatment; she liked to use herbs and traditional medicines. I came for treatment but later I disappeared, that's why I am saying I started treatment long time back. I disappeared and did not come to the facility until I became ill again after the death of my grandmother. While she was alive, I was not taking my medication because she instructed me not to come to the facility."* [Participant 3 –18 years old].

Adolescents reported that their family members are not fully engaged in their care. For example, one participant who was staying with his/her mother was not attending services as required, as he/she was "bored" by having to attend the clinic so frequently. The adolescent stopped going to the clinic and since the mother did not take the initiative to inquire from the facility regarding the frequency of her child's attendance, the child defaulted on treatment. In another situation, the adolescent was part of a child-headed household and due to his siblings taking on adult responsibilities and other more pressing challenges, they could not encourage him to take medication or go to the facility.

> *"I used to go to the veld, and I slept there where we keep our animals, I was not able to take my pills properly…I forgot until my brother asked me whether I still go to the facility."* [Participant 10 – 15 years old].

Participants verbalised that when they got support from family members, their attendance improved. In some instances, the healthcare workers had to assist by addressing the issue of support from family members or any other responsible adult.

For example, they had to request relatives of an adolescent staying in a child-headed family, to supervise medication adherence. When support was addressed, the adolescents were able to come to the facility as expected and they took their medication well.

> *"Then I was transferred from that facility I was previously taking drugs to this present one, then I went to stay with my grandmother; while I was staying with my grandmother, I took my medication properly. There was a time when we had misunderstanding, then I stopped taking my medication and then I was taken to a foster home, where I am staying and now, I am taking my medication properly.... No, she expelled me from her family, so I left my medication there… I was staying on the street; my shelter was old non-functioning vehicles."* [Participant 5 – 15 years old].

Relatives who were approached by the healthcare workers supported the adolescents to take their medication and they encouraged them to go to the facility for follow-up.

> *"They ask me whether it is not time to take my medication. They make sure that I have swallowed the pills. When I look into the booklet* (health booklet which every client should have when attending health facility for healthcare worker to document client health information) *they also look at it."* [Participant 10 – 15 years old].

Some adolescents expressed how they are supported by family members – instrumentally and emotionally. One participant expressed that after collecting the medications from the facility, he gives them to his caretaker to take them home because he does not want to take them to school.

Another participant expressed that his aunt explained everything to him regarding his condition and that gave him the courage to accept his status and he took his medications.

> *"My aunt explained that I got the infection from my parents, I accepted it."* [Participant 4 – 19 years old].

Lack of support from family members affected the health service attendance of the adolescents, but nevertheless, the minimal support that they received motivated them to attend services.

4.3.4.2 Support from friends

There is an expectation that in time of need, friends are people who should provide reciprocal support. With mutual friends, an individual has no fear about talking openly about his/her emotions, mood and feelings. There is also an element of trust and understanding with friends (Encyclopaedia Britannica, Merriam-Weber, s.v. "friend"). By contrast, adolescents were worried that they will be embarrassed when their friends find out that they are taking ARVs. They articulated that their friends teased and giggled at them in a ridiculing way and they asked them why they were taking ARVs at their age. This behaviour of friends or peers discouraged the adolescents from attending clinic appointments. The participants expressed that they did not want their friends to know that they took ARVs. Two participants even voiced that they did not want to go back to school with their medicine after they had collected it from the facility.

> *"I do not like that some of my friends should know that I take pills… It is because they laugh at us."* [Participant 10 – 15 years old].

> *"Challenges that we face are they give us pill in bottles; they do not put them in the pill bags. Sometimes we collect them while we are at school, during school time we return to school our friends get hold of our bags, they hear the sound of pill in our school bags, and they laugh at us... They shake our bags, and then they ask us why we take ARVs at our age."* [Participant 11 – 18 years old].

Adolescents who got support from their friends were motivated to visit the health facility for their services. One of the participants expressed that he feels comfortable to come to the facility because his friend is also taking ARVs.

> *"There is none because my friend also takes medication, we are always together."* [Participant 5 – 15 years old].

Friends living with HIV were a source of support, but friends without the HIV infection teased their adolescent friends for taking ARVs.

4.3.4.3 Community support

Some of the community members who knew about the adolescent's condition supported them. Community members such as teachers would even advise the adolescents to go to the facility before the class begins so that they do not miss tutorials. One adolescent mentioned that a member of his community was concerned about his welfare to such an extent that she escorted him to the facility to make sure that he received help. This support conveys love and acceptance.

> *"I was brought by my former teacher at primary school I came here with her. She is my grandmother's neighbour."* [Participant 5 – 15 years old].

> *"Class teacher encourages me to come to the facility early in the morning not in the afternoon. No, I go to school attend study class then after that I request permission and come to the facility, sometimes I am told that when permission has been granted, I can go back to school when I like or I cannot go after services. Sometimes I do not go back to school, then people that I share a desk with they are ordered to write school notes for me."* [Participant 10 –15 years old].

Apart from the above-mentioned examples, the participants did not mention other types of community support. Community involvement in the provision of health services is vital. It encourages the usage of such services by most members of the community thus combating HIV-related stigma.

> *"Last year, after the death of my sister I thought of stopping to take my medication because there was no one to take care of me because my mother died while I was still young. But the counsellor at the facility encouraged me to continue. Other reason can be stigmatization; if you are not strong you can stop them."* [Participant 11 – 18 years old].

Some of the community members provided support to adolescents even though most of them did not.

4.3.5 Theme 5: The expectations regarding health care services

Adolescents as the consumers of health care services do have expectations from health facilities where they access services. These expectations will be discussed below, as mentioned by the participants.

4.3.5.1 Health services

The adolescents expressed several expectations regarding health services in addition to what is currently offered at the facilities. In one of the facilities where services are provided from Monday to Friday, the adolescents suggested that services should be given on a Friday after school or on a Saturday when they do not go to school. They also expressed that health service appointments should not interfere with their school attendance.

> "*Like as they close at four o'clock, we should come on Friday after lunch because the school ends at one o'clock."* [Participant 11 – 18 years old].

> *"If we go on Saturdays* (for services) ---- *I hated that after* (attending health services during the week days) *that I had to copy a lot of school notes, I had to borrow other's notes to write notes which were written while I was away."* [Participant 8 – 14 years old].

Adolescents seemed to be concerned about privacy and confidentiality, to such an extent that one participant expressed that pills should be dispensed in pill bags when they are supplied during the week.

> *"What I am concerned about is the pills that are in the bottle, I request that they should be dispensed in a pill bag and that when we come during the week, we should be appointed on Friday only."* [Participant 11 – 19 years old].

The adolescents need to be involved in the planning and in the provision of their health care services. Decisions for allocating days to come for services and how those services would be provided should be done in collaboration with them.

4.3.5.2 Entertainment

Entertainment is any activity that gives gratification and holds the attention and the interest of individuals (Dictionary.com, LLCC, 2019, s.v. “entertainment”). The adolescents expressed that there should be space for entertainment for them to utilise when they attend health services. They also suggested that there should be computers at the facilities with access to the internet. They mentioned that they should be given the opportunity to play computer games after being attended to. The adolescents claimed that there should be a space to play. One participant expressed that they should have vocational trips to other places where they would be able to meet their peers.

> *“I wish there could be games when we have come for check-ups, computer games. Have more vocational trips.”* [Participant 2 – 18 years old].

Adolescents also wish to have enough space for playing games such as soccer. They should have enough balls and other games to play with at the health facilities. Participants preferred active and non-active games equally.

> *“From there as we attend ‘Wise Youth’ sometimes we like to play but we do not have balls and some of us we enjoy playing ball.”* [Participant 4 – 18 years old].

Pleasurable activities were one of the concerns mentioned by the adolescents to make facilities adolescent-friendly. Entertainment equipment was identified as being limited in both facilities.

4.4 CONCLUSION

The findings of the study have been presented in this chapter. Themes and sub-themes were identified from the data. The findings were interpreted, based on the objectives of the study. In the next chapter, a discussion of the findings in relation to the literature, the conclusion and the suggested recommendations are presented.

CHAPTER 5

DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

In the previous chapters, the background to the study was mentioned, the literature related to the experiences of adolescents living with HIV was discussed and a detailed discussion of all the steps of the research process applied in conducting the study was provided. The objectives of the study and the measures to provide trustworthiness were mentioned. The findings of the study were also presented. In this chapter the findings are discussed in relation to the literature and recommendations are made. Finally, the researcher presents the conclusions, identifies the limitations and recommends areas for future research.

5.2 DISCUSSION

The research aimed to explore and to describe the experiences of adolescents living with HIV, regarding attending healthcare services in the Botha-Bothe District in Lesotho. The findings are based on interviews that were done with participants who attend Baylor and Ngoajane health facilities. In the next sections, the findings concerning the study objectives and the current literature are discussed.

5.2.1 Objective 1: Describe the experiences of adolescents living with HIV regarding the physical environment of the health facility

The themes are discussed as they relate to each of the objectives. The two sub-themes that relate to this objective are space for entertainment, relaxation and educational materials.

5.2.1.1 Dedicated space

Dedicated space is needed in the health facilities to allow adolescents to interact with peers and to share their experiences. The qualitative studies done by Smith et al. (2018:679) on what South African adolescents want in a sexual health service, and Mutumba et al. (2017:5) concerning Ugandan adolescents' preferences for strategies for HIV self-management, indicated that there should be dedicated space for them to interact and to discuss their problems in a comfortable environment. A

systemic review of indicators of youth-friendly care, drawn from young people's perspectives revealed that adolescents advocate for separate physical space at health care facilities (Ambresin, Bennett, Patton, Sanci & Sawyer, 2013:679). A dedicated space and age-appropriate activities in facilities may further encourage and sustain cognitive skills, tactical thinking and problem-solving for ALHIV (Goldstein, 2012:6). In the present study, it was found that the facilities do not have dedicated spaces for adolescents. Some of the adolescents were not aware of whether such spaces exist in the facility. Studies conducted in the United States of America (Tanner et al., 2013:5) and in Zambia (Mburu et al., 2014:15), found that the availability of dedicated space allows adolescents to interact with health care workers and engage with peers.

Health facilities are built in such a way that there are rooms for counselling and consultations only. Health facilities do not have dedicated spaces for adolescents and there are no facilities for entertainment. The study by Mutumba et al. (2018:5) found that adolescents prefer entertainment activities available when attending health facilities. Tanner et al. (2013:5) recommended that a dedicated space should be decorated and designed to attract adolescents. The space should be up to date with the present needs of adolescents. Participants from the same study mentioned that there should be entertainment materials such as magazines and television available. Adolescents prefer to obtain services in an environment that is designed specifically for them and their needs (Ambresin et al., 2013:679).

The present study found that entertainment activities such as dance, music, drama, and aerobics are facilitated outside the building when adolescents attend the club on the premises, on weekends. There are no indoor activities provided when adolescents are waiting for services. Indoor activities are important to foster informal interaction. Music is not played when adolescents come for services; it is only played on weekends during club activities. Health facilities do not have computers for adolescents to use when they attend appointments; hence adolescents are not able to play computer games. Mutumba et al. (2018:5) found that adolescents advocated for eHealth technology, i.e. electronic technological applications through mobile phones or computers that are used to convey health information.

Mwaba, Ngoma, Kusanthan and Menon (2015:4) mentioned that children living with HIV may develop learning, conduct, and anxiety problems. The space for entertainment and specific activities would provide an opportunity for adolescents to play. Play may ease their minds, damp down angst, oppression, and petulance. Furthermore, play can repair emotional pain and increase tranquillity, toughness, and flexibility (Goldstein, 2012:6).

5.2.1.2 Health facility surroundings

Adolescents were satisfied with the physical environment of the health facilities. They expressed that their health facilities' surroundings are clean. Adolescents expressed their gratitude that they are provided with services in a clean and attractive environment. Adolescents also liked to play sports outside the facilities. Cleanliness of the environment is one of the elements of patient satisfaction (Wouters, Heunis, Van Rensburg & Meuleman's, 2008:3; Ambresin et al., 2013:679; WHO, 2015:11). According to the WHO (2015:11), global standards should be set for adolescent services and health facilities should be clean.

5.2.1.3 Availability of educational materials

Age-appropriate educational materials such as books, pamphlets, and posters are not present in the health facilities included in this study. Adolescents need information about HIV and sexuality, so that they can make informed decisions regarding their care and their treatment. Lack of information is a contributing factor to poor adherence to treatment (Southern African HIV Clinicians Society, 2017:36; Mutumba et al., 2017:4; Zanoni et al., 2018:963).

In the facilities included in this current study, there are no books and pamphlets written in a language and on a reading level that adolescents can understand. There are no adolescent-specific posters against the wall. Information is shared mostly during health education sessions. In a study done in Soweto, South Africa, adolescents living with HIV stipulated that educational materials should be available, and they should be written in a simple-enough language for them to understand. Adolescent caregivers should also be given educational materials that will assist them in knowing how to handle adolescent issues (Hornschuh et al., 2014:428). Global standards for adolescent services indicate that health literacy is a key

component of quality care and that health facilities should make sure that adolescents know about their health status and how to navigate the health system to get health services when the need arises (WHO, 2015:5).

The participants of the present study mentioned that healthcare workers did not always use words that they could understand when giving information. It further appeared that healthcare workers did not always use an age-appropriate approach to communicate. One of the participants stipulated that he felt threatened by the information given by the healthcare workers.

Armstrong *et al.,* (2018:44) commented that the information that is given is not conveyed in such a way that it attracts an adolescents' interest. Ambresin et al. (2013:678) found that adolescents want healthcare workers to convey technical information directly to them; but that they must not use formal communication strategies (it must be communicated on their level). When information is not adequately conveyed, adolescents may access the wrong information from other sources of information such as friends.

5.2.2 Objective 2: Describe the experiences of adolescents in the social environment and their interaction with healthcare workers

Two themes were identified concerning this objective. These themes are social environment and support. The social environment and the interaction with healthcare workers will be discussed in three sub-themes, namely relationships with healthcare workers, confidentiality and support.

5.2.2.1 Relationship with healthcare workers

Communication between participants and health care workers was challenging. It seemed that it was difficult to communicate effectively because of the generation gap and the adolescents' stage of development. Despite this, certain healthcare workers graciously dealt with adolescents and they encouraged them throughout their tenure. Similarly, the literature presents mixed findings pertaining to the relationship of adolescents with healthcare workers and the communication between healthcare workers and adolescents.

A qualitative study by Hornschuh et al. (2014:247) showed that adolescents were satisfied with the communication skills of healthcare workers. Conversely, in studies conducted by Zanoni *et al.,* (2018:961), Armstrong *et al.,* (2018:44), WHO (2010:35), and Crowley (2018:156), adolescents expressed that health facility staff do not always talk to them in an acceptable way when they attend appointments. WHO (2015:9) emphasized that healthcare workers should have technical and attitudinal competencies to provide effective health services to adolescents.

In the present study, good communication was based on (or a result of) good attendance. For example, when adolescents attended their appointments as scheduled and they were adherent to treatment, they were treated with respect. On the other hand, healthcare workers did not address issues such as missing appointments without showing emotion and sometimes blatantly communicated their disapproval of an adolescents' behaviour. Healthcare workers also reprimanded adolescents when they did not take their medication appropriately. It also appeared that healthcare workers sometimes showed a lack of interest in communicating with adolescents. Participants expressed that most of the healthcare workers spent time on their cell phones, rather than talking to them.

Effective communication allows adolescents to relax, speak openly and in the end, healthcare workers can appreciate their problems and their needs (Zanoni *et al.,* 2018:960). Healthcare workers should not consider adolescents as inferior and undermine their knowledge. Respect is also a key aspect of caring for adolescents.

Adolescents in the present study mentioned that it is difficult to form a trusting relationship with healthcare workers. Healthcare workers are rotated, or they are often transferred. Adolescents also indicated that the frequent changing of healthcare workers affected them negatively because it is not easy to entrust their information to people who are constantly changing. Smith et al. (2018:679) also found that adolescents can share their information more easily and freely with people who they trust.

5.2.2.2 Confidentiality

Adolescents preferred not to be seen when they visit health facilities that provide HIV services. HIV-related stigma makes people feel uncomfortable about attending

services. Adolescents do not want to be associated with health facilities that provide HIV services. At both clinics where the study was conducted, services are provided in rooms where privacy is paramount. However, one health care facility is not fenced in such a way that other people in the community do not see what is happing around the facility. Confidentiality and privacy were concerns for some adolescents. Adolescents are sensitive due to the prevailing HIV stigma in communities. According to WHO (2015:11), the health facility should be designed in such a way that it provides privacy and confidentiality.

In other settings, a lack of confidentiality has been identified as a problem but not in this study. For example, a study that was done in South Africa (Hornschuh *et al.,* 2014:426) and the survey conducted by WHO (2013(a):4), found that health care workers discussed an adolescents' condition, results and treatment with each other even in the presence of other people.

5.2.2.3 Support

Family and peers contribute to the social environment of the health care facility as they play a supportive role. WHO (2015:6) stipulated that health facilities should make sure that parents, guardians, and the community appreciate the provision of health services to adolescents and support the initiative. The present study found that family members seemed to be involved minimally in the care and the treatment of adolescents.

It appeared that the adolescents' grandmothers expected them to attend services on their own because they are older. Sometimes adolescents forgot to take their medication because there was no one around to remind them. Studies by Adams (2017:61) and Mutumba *et al.,* (2017:4) revealed that the lack of support from caregivers jeopardizes the care of ALHIV. Conversely, there were examples of community involvement. In some instances, community members who knew about the adolescent's condition supported them.

Community members such as teachers would even advise adolescents to go to the facility before the class began so that they did not miss tutorials. Other healthcare workers also intervened in some instances; for example, one healthcare worker encouraged adolescents to take their treatment at her place. These community

members valued the provision of health care and the support of ALHIV patients who utilize such services (Mutumba *et al.,* 2017:5)

5.2.3 Objective 3: Determining the types of health services utilized by adolescents living with HIV

Services were identified as a theme from the collected data. This theme had two sub-themes, namely accessible services and timing of services. The timing of services does not specifically relate to this objective, but it is discussed here, since it relates to how services should be provided.

5.2.3.1 Accessible services

Services that adolescents use in the facilities are counseling and HIV care and treatment. Counseling is provided as part of the HIV care and treatment package. Preventive services such as contraceptive services were not mentioned by most of the adolescents; adolescents received information about these services but did not report using them.

Most of the participants could not verbalize the other types of care that are accessible in the facilities. There are no studies found which identified the services utilized by adolescents living with HIV.

Gage *et al.,* (2017:22) stipulated that the diagnosis and the treatment of sexually transmitted infection (STIs), mental health and social services should be available for adolescents. Global standards for quality health care services for adolescents recommend that information, counseling, diagnostic treatment and care should be provided to adolescents, to address all their needs. There should also be a system in place for referral and outreach services (WHO, 2015:7). The adolescents currently do not receive a comprehensive package of care.

5.2.3.2 Timing of service provision

Adolescents are appointed to come on certain days for services. The frequency and timing of attendance are determined by the healthcare workers. The times and the days that are allocated for service delivery were acceptable for some of the adolescents, but not for all.

The adolescents preferred services to be provided when they were not going to school, since they did not want to miss classes.

Similarly, the WHO (2013(b):13) survey found that some adolescents reported that health facility appointments disturbed their usual activities. They preferred scheduling appointments after school, so that they do not miss school.

Several other studies found that health facility attendance affected adolescents' daily activities (Adams, 2017:52; Mburu et al., 2014:15; Zanoni *et al.,* 2019:958). Adolescents mentioned that they fall behind with schoolwork on those days when they are attending health care services (Adams, 2017:52).

The present study also found that schedules for health facility visits are not flexible enough to accommodate adolescents' needs. Adolescents said that they wished that the timing of service delivery was discussed with them. Adolescents have preferred times to come for services. Adolescents were also disturbed by having to come to the facility frequently. For example, one of the participants expressed that it was not fair for them to have to come to the facility frequently.

The adolescents revealed that healthcare workers did not explain thoroughly enough the reason for coming to the health facility frequently. Due to the lack of collaboration in planning adolescents' care, some of them decided not to attend as appointed. Zanoni *et al.,* (2019:959) also found that having to attend health facility services frequently is a barrier to attending services. WHO Global Standards (2015:11) emphasize that the health facility should provide services to adolescents at a suitable time, to meet their needs.

5.2.4 Objective 4: Identify an adolescents' expectations regarding health services

Expectations regarding health care services is the theme identified that relates to this objective. Sub-themes that will be discussed are health services and entertainment.

5.2.4.1 Health services

Adolescents suggested that services should be provided on a Friday after school or on a Saturday, when they are not attending school. They also expressed that health service appointments should not interfere with their school attendance. This is similar

to what was reported by WHO (2013(b):13) and a study conducted in KwaZulu-Natal, South Africa (Zanoni *et al.,* 2018:559-960). Two qualitative studies conducted in South Africa similarly found that adolescents preferred to attend services after school (Hornschuh *et al.,* 2014:428; Adams, 2017:52).

Adolescents seemed to be concerned about privacy and confidentiality to such a degree that one participant expressed that pills should be dispensed in pill bags when they are given services during the week. It is important to provide services in a safe and confidential environment.

Adams (2017:45) found that adolescents feel that people will treat them badly if they know that they are HIV positive. Medication and other services should be provided behind closed doors.

An adolescents' information should not be shared without their knowledge (Southern African HIV Clinicians Society, 2017:21). Confidentiality and privacy should be deemed important when providing services to adolescents (Gage *et al.,* 2017:23; Crowley, 2017:153).

5.2.4.2 Entertainment

Adolescents expressed that there should be space for entertainment for them to utilize when they attended services. They suggested that there should be computers at facilities with access to the internet. They mentioned that they should be allowed to play computer games.

In the facility where there are few ALHIV patients attending service, one or two computers could be installed so that adolescents have access to them.

In the facility where many ALHIV patients are attending services, it might be challenging to provide computer access to all of them. The facilities may source funds to purchase a few computers as a starting point.

Gage *et al.* (2017:8) reported that best practices for care for ALHIV includes the use of technology to share information. One participant expressed that they should have vocational trips to other places where they will be able to meet their peers.

5.3 RECOMMENDATIONS

Recommendations are derived from the study findings and they are summarized in Table 5.1 below.

Table 5.1: Summary of recommendations on the physical and social environment

Objectives	Recommendations
The experiences of adolescents living with HIV about the health facility physical environment.	1. Avail dedicated space (for entertainment and to relax). 2. Provide age-appropriate educational materials.
The experiences of adolescents in the social environment and their interaction with healthcare workers.	3. Encourage care partnerships.
Types of health services utilized by adolescents living with HIV.	4. Provide comprehensive adolescent-friendly services.

5.3.1 Recommendation 1: Provide dedicated space (for entertainment and to relax)

Health facilities should avail dedicated spaces (for entertainment) to adolescents when they come for services. Space to relax can also be provided to allow adolescents to reduce tension. Health facilities should provide a safe and a supporting environment (WHO, 2015:11). Adolescents feel that it is important to have such spaces, so that they can meet their peers and discuss their challenges. Dedicated space also allows healthcare workers to be with the adolescents and to involve them in learning and discussion of sensitive issues. Adolescents should be able to voice their concerns and needs in a relaxed state (Tanner et al., 2014:5).

5.3.2 Recommendation 2. Provide age-appropriate educational materials

Health facilities should provide adolescents with educational materials such as pamphlets, storybooks and picture books. The government should acquire these educational materials and distribute them to the facilities. These materials should give information in a simple but interesting manner. They should also be translated into the local language and on literacy level that's understandable for adolescents (WHO, 2015:5). Posters should be put on the walls for adolescents to read. Materials such as books, television series, and games could be used to provide

information to adolescents attractively and interestingly (Tanner et al., 2014:5). Known and new information can be shared, using different materials such as videos, youth-oriented smart phone applications and a one on one session (Southern African HIV Clinicians Society, 2017:51).

5.3.3 Recommendation 3: Provide comprehensive adolescent-friendly services

Health facilities should provide all health services that are important for an adolescents' wellbeing. These services should be made known to all adolescents. Health services should address all adolescents' needs, be accessible to all adolescents and should benefit all adolescents. Comprehensive adolescent-friendly services should include sexual reproductive health and prevention of HIV transmission to others, treatment of other illnesses and HIV, information sharing and care and support (Armstrong *et al.,* 2017:25). Adolescents should also be counselled regarding their future careers (Mutumba *et al.,* 2018:5). These services should meet the needs of all adolescents (Armstrong *et al.,* 2017:25). Adolescents should be able to access these services at any time and they should not have to wait for services for a long time (WHO, 2015:4).

5.3.4 Recommendation 4. Encourage care partnerships

Policies should be developed to guide all health facilities on the involvement of parents, caregivers, and adolescents in planning an adolescents' care. Where there are available policies they should be implemented. Policies should be disseminated to all stakeholders in an adolescents' care (WHO, 2015:6). Decisions taken by healthcare workers regarding an adolescent's care should be made in collaboration with adolescents.

Healthcare workers should be trained in communication and adolescent-specific care. Adolescents should know about the services available for them to utilize and they should be included in the planning of such services. Adolescents should also be able to evaluate the way they are given such services and they should know their rights (WHO, 2010:35).

Adolescents should be engaged in their care and treatment and should be able to express any challenges that they encounter with health care providers, in a positive

manner (Southern African HIV Clinicians Society, 2017:40). What was learned from this study is that a dedicated service for adolescents does not necessarily mean that it is adolescent-friendly. I recommend that specific standards should be set as per WHO guidelines and that these should be measured and quality improvement projects initiated.

5.4 FUTURE RESEARCH

In this study, experiences of adolescents living with HIV attending health services were described. The study can be repeated in other contexts. More health facilities may be used, and many participants can be interviewed. A larger quantitative study could be conducted on adolescent satisfaction with services using a tailored satisfaction survey. Healthcare workers' competencies to deliver adolescent-friendly services should be investigated. I would also recommend quality improvement research related to implementing the Global Standards for Quality Health Care Services for Adolescents (WHO, 2015).

5.5 LIMITATIONS OF THE STUDY

Female adolescents were more likely to refuse to participate, compared to males. Only two agreed to be interviewed. Therefore, the voices of females are underrepresented in this study. I had trouble in recruiting participants, and I could not recruit an equal number of participants across all age groups and facilities. The findings of the study may not be generalizable, but it should be applicable in other settings with similar participants (Nowell, Norris, White & Moules, 2017:3).

5.6 PERSONAL REFLECTION

I identified personal opinions and past experiences which may affect the research process, before the study. Although I used my past experiences in the study to provide context, I set aside my personal opinions and I tried to be as factual and neutral as possible (Ritchie et al., 2014:20). I have worked at primary health care facilities in the district for thirteen years. However, I did not work at the Ngoajane or at the Baylor facilities before conducting the research study. I experienced providing HIV services to adults and to children under fourteen (14 years) of age.

I started to provide services to adolescents living with HIV in 2014. Most of the adolescents were under the age of fourteen (14). I observed that when the adolescents reached the age of fourteen (14) there was a change in their attendance at the health facility. Their appointments became more irregular until some of them stopped coming to the facility. Some even refused to come to the facility to collect their treatment. My preconception and my bias are that adolescents are a very difficult group to work with.

I am currently working at the District Health Management office as part of the management team and I do not interact with clients at health facilities. The workshops that I attended concerning adolescents' health guided me on how to handle adolescents. Due to my prior knowledge and my son also being in the adolescence stage, I thought that it would be easy for me to get information from adolescents about their experiences. On the contrary, it was not an easy journey to take. The age difference between me and the participants also contributed to the challenges that I experienced with data collection.

During data collection, it was not easy for adolescents to be open and willing to be interviewed. I had to go to the facilities several times to gain their trust. However, during the interviews, most adolescents were open, and they articulated their experiences.

5.7 CONCLUSION

The research aimed to describe the experiences of adolescents living with HIV regarding health services. The study found that health facilities do not have dedicated space to allow adolescents to interact with peers and share their experiences. It is difficult for healthcare workers to communicate effectively with adolescents because of the generation gap.

Services that adolescents use in the facilities are counseling and HIV care and treatment. Adolescents preferred scheduling appointments after school so that they do not miss school. Health facilities should provide adolescents with educational materials and health services that address all their needs. Healthcare workers should be trained in communication and adolescent-specific care.

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APPENDICES

APPENDIX 1: ETHICAL APPROVAL FROM STELLENBOSCH UNIVERSITY

UNIVERSITEIT
STELLENBOSCH
UNIVERSITY

Health Research Ethics Committee (HREC)

Approval Notice

New Application

17/05/2018

Project ID :6275

HREC Reference # S18/02/022

Title: Adolescent-friendly services: Experiences of adolescents living with HIV infection attending health services in Butha-Buthe District Lesotho (2)

Dear Ms Mamoferefere Tatapa zim Mabandla

The **New Application** received on 25/04/2018 19:32 was reviewed by members of **Health Research Ethics Committee** via **expedited** review procedures on 17/05/2018 and was approved.

Please note the following information about your approved research protocol:

Protocol Approval Period: **This project has approval for 12 months from the date of this letter.**

Please remember to use your project ID (6275)on any documents or correspondence with the HREC concerning your research protocol.

Please note that the HREC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

After Ethical Review

Translation of the informed consent document(s) to the language(s) applicable to your study participants should now be submitted to the HREC.

Please note you can submit your progress report through the online ethics application process, available at: Links Application Form Direct Link and the application should be submitted to the HREC before the year has expired. Please see *Forms and Instructions* on our HREC website (www.sun.ac.za/healthresearchethics) for guidance on how to submit a progress report.

The HREC will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.

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Provincial and City of Cape Town Approval

Please note that for research at a primary or secondary healthcare facility, permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Please consult the Western Cape Government website for access to the online Health Research Approval Process, see: https://www.westerncape.gov.za/general-publication/health-research-approval-process. Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

We wish you the best as you conduct your research.

For standard HREC forms and instructions, please visit: Forms and Instructions on our HREC website https://applyethics.sun.ac.za/ProjectView/Index/6275

If you have any questions or need further assistance, please contact the HREC office at 021 938 9677.

Yours sincerely,

Mr. Franklin Weber

HREC Coordinator

National Health Research Ethics Council (NHREC) Registration Number:

REC-130408-012 (HREC1)•REC-230208-010 (HREC2)

Federal Wide Assurance Number: 00001372
Office of Human Research Protections (OHRP) Institutional Review Board (IRB) Number:
IRB0005240 (HREC1)•IRB0005239 (HREC2)

The Health Research Ethics Committee (HREC) complies with the SA National Health Act No. 61 of 2003 as it pertains to health research. The HREC abides by the ethical norms and principles for research, established by the World Medical Association (2013). Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects; the South African Department of Health (2006). Guidelines for Good Practice in the Conduct of Clinical Trials with Human Participants in South Africa (2nd edition); as well as the Department of Health (2015). Ethics in Health Research: Principles, Processes and Structures (2nd edition).

The Health Research Ethics Committee reviews research involving human subjects conducted or supported by the Department of Health and Human Services, or other federal departments or agencies that apply the Federal Policy for the Protection of Human Subjects to such research (United States Code of Federal Regulations Title 45 Part 46); and/or clinical investigations regulated by the Food and Drug Administration (FDA) of the Department of Health and Human Services.

Appendix 2: Permission obtained from the Ministry of health research coordinating unit and institutions

LESOTHO

Ministry of Health
PO Box 514
Maseru 100

REF: ID115-2015

Date: June 26 2018

Category of Review:
[x] Initial Review
[ ] Continuing Annual Review
[ ] Amendment/Modification
[ ] Reactivation
[ ] Serious Adverse Event
[ ] Other _____

To
Mamoferefere T. Z. Mabandla
Masters in Nursing candidate
University of Stellenbosch, SA

Dear Ms. Mamoferefere,

RE: Adolescent-friendly services: Experiences of adolescents living with HIV infection attending health services in Butha-Buthe District Lesotho

This is to inform you that on 16June 2018the Ministry of Health Research and Ethics Committee reviewed and **APPROVED** the above named modified protocol and hereby authorizes you to continue the study according to the activities and population specified in the protocol. Departure from the approved protocol will constitute a breach of this permission.

This approval includes review of the following attachments:
[x] Protocol dated 18/05/18
[x] English & Sesotho parent consent forms
[X] Interview guide English & Sesotho dated 18/05/18
[ ] Data collection forms in English
[X] Participant materials *[Information leaflet and assent form]* dated 18/05/18
[X] Other materials: CV of the applicant
This approval is **VALID** until June 25 2019.

Please note that an annual report and request for renewal, if applicable, must be submitted at least 6 weeks before the expiry date.

All serious adverse events associated with this study must be reported promptly to the MOH Research and Ethics Committee. Any modifications to the approved protocol or consent forms must be submitted to the committee prior to implementation of any changes.

We look forward to receiving your progress reports and a final report at the end of the study. If you have any questions, please contact the Research and Ethics Committee at rcumoh@gmail.com (or) 22226317.

Sincerely,

Dr. Nyane Letsie
Director General Health Services

Dr. Amelia Ranotsi
Chairperson NH-IRB

District Health Management Team

P.O.Box 32

Butha-Buthe

Lesotho

21/05/18

The Head

Baylor College of Medicine Children Foundation

Maseru

Lesotho

RE: Permission to conduct Research Study

Dear Dr/Mr/Mrs,

I am writing to request permission to conduct a research at your satellite health facility at Butha-Buthe.I am currently enrolled for the Masters of Nursing degree at Stellenbosch University and am in the process of writing my masters thesis. The study is entitled Adolescent-friendly services: Experiences of adolescents living with HIV infection attending health services in Butha-Buthe District Lesotho.

If you agree, kindly sign below and return the signed form in the enclosed self-addressed envelope.

Alternatively, kindly submit a signed letter of permission on your institution's letter head acknowledging your consent and permission for me to conduct this study at your institution.

Sincerely

Mamoferefere Tatapa Zim Mabandla

Approved by

Jill Sanders Associate Director		25.7.2018
Print name and title	Signature	Date

District Health Management Team

P.O Box 32

Butha-Buthe

Lesotho

4/6/18

The nurse in charge

Ngoajane health centre

Butha-Buthe

RE: Permission to conduct Research Study

Dear Dr/Mr/Mrs,

I am writing to request permission to conduct a research at Ngoajane health centre. I am currently enrolled for the Masters of Nursing degree at Stellenbosch University and am in the process of writing my master's thesis. The study is entitled Adolescent-friendly services: Experiences of adolescents living with HIV infection attending health services in Butha-Buthe District Lesotho. I hope the institution will allow me to recruit adolescents from the institution to be interviewed. Due to the nature of the study, I will obtain parental consent and child assent for those participants who are under eighteen years.

If approval is granted, participants will be interviewed in a quiet room at the institution or at a place preferred by the participant.

Findings will remain confidential and no personal details of participants will be divulged. No cost will be incurred by the institution or individual participants.

Your approval to conduct this study will be greatly appreciated. I will follow up with a telephone call and will be happy to answer any questions or concerns that you may

have at that time. You may contact me at my email address:zmamoferefere@yahoo.com.

If you agree, kindly sign below and return the signed form in the enclosed self-addressed envelope.

Alternatively, kindly submit a signed letter of permission on your institution's letter head acknowledging your consent and permission for me to conduct this study at your institution.

Sincerely

Mamoferefere Tatapa Zim Mabandla

Approved by

MASELCA KENELICE
NURSING OFFICER

NGOAJANE
HEALTH CENTRE
20 JUN 2018

20/06/18

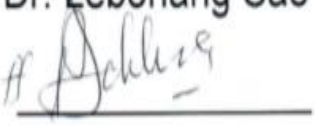
Print name and title | Signature | Date

MEMO

FROM : District Medical officer

TO : Health Facility Managers

NAME : Dr. Lebohang Sao

SIGN : 

DATE : 02/07/2018

Re: Authorization to conduct study on adolescent-friendly services: experiences of adolescents living with HIV infection attending health services in Botha-Bothe district

The office of District medical officer has authorized Mamoferefere Tatapa Zim Mabandla to conduct the study in specified health facilities as protocol approved by Ministry of health research coordinating unit.

Your usual cooperation will be highly appreciated.

APPENDIX 3: PARTICIPANT INFORMATION LEAFLET AND DECLARATION OF CONSENT BY PARTICIPANT AND INVESTIGATOR

ADOLESCENT PARTICIPANT INFORMATION LEAFLET AND ASSENT FORM

TITLE OF THE RESEARCH PROJECT: Experiences of adolescents living with HIV and attending healthcare services in Botha-Bothe District, Lesotho.

RESEARCHER NAME(S): Mamoferefere Tatapa Zim Mabandla
ADDRESS: Lipelaneng Ha kamoho
P.O. Box 32, Botha-Bothe, Lesotho
CONTACT NUMBER: +266 59184558

WHAT IS RESEARCH?

Research is something we do to find new knowledge about the way things (and people) work. We use research projects or studies to help us find out more about disease or illness. Research also helps us to find better ways of helping or treating children who are sick.

WHAT IS THIS RESEARCH PROJECT ALL ABOUT?

The purpose is to explore and describe the experiences of adolescents living with HIV infection in respect of the healthcare facility's physical and social environment, their interaction with healthcare workers, and to identify their expectation of healthcare services. The study will be conducted at the Ngoajane Health Facility and the Baylor Health Facility. This study has been approved by the Health Research Ethics Committee at Stellenbosch University.

WHY HAVE I BEEN INVITED TO TAKE PART IN THIS RESEARCH PROJECT?

You have been invited to participate in the study because you are considered to have relevant knowledge of the situation.

WHO IS DOING THE RESEARCH?

The interview will be conducted by the researcher and will be audiotaped; the interviews will not be shared with any person without your permission. I am a nurse working at the District Health Management Team Department, and I am doing the research as part of my studies at the University of Stellenbosch.

WHAT WILL HAPPEN TO ME DURING THIS STUDY?

You will be interviewed about your experiences in respect of healthcare services in the health facility. The interview will take 40 to 60 minutes. **CAN ANYTHING BAD HAPPEN TO ME?**

The interview might cause fatigue. You can take a rest/break at any time. You may feel emotional or upset when answering some of the questions. You can tell the interviewer at any time if you want to take a break or to stop the interview.

CAN ANYTHING GOOD HAPPEN TO ME?

There is no direct benefit to you from being part of this study. However, your participation may help others in the future, as a result of knowledge gained from the research.

WILL ANYONE KNOW I AM PART OF THE STUDY?

Your identity will not be revealed while the study is being conducted, and when it is reported or published.

WHO CAN I TALK TO ABOUT THE STUDY?

You can contact the Health Research Ethics Committee on 021-938 9207, if you have any concerns or complaints that have not been adequately addressed by the researcher.

My supervisor is Mrs Talitha Crowley.

Contact number: +27219389625

WHAT IF I DO NOT WANT TO DO THIS?

Your participation is entirely voluntary, and you are free to decline to participate. If you say no – this will not affect you negatively in any way.

Do you understand this research study and are you willing to take part in it?

YES	NO

Has the researcher answered all your questions?

YES	NO

Do you understand that you can pull out of the study at any time?

YES	NO

_____ _____

Name and signature of adolescent Date

INFORMED CONSENT FORMS

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM FOR ADOLESCENTS 18 YEARS AND OLDER

TITLE OF THE RESEARCH PROJECT: Experiences of adolescents living with HIV attending healthcare services in Botha-Bothe District Lesotho.

REFERENCE NUMBER: 21362610

PRINCIPAL INVESTIGATOR: Mamoferefere Tatapa Zim Mabandla

ADDRESS: Lipelaneng Ha kamoho
P.O. Box 32
Botha-Bothe
Lesotho

CONTACT NUMBER: +26659184558

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the researcher any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved.
This study has been approved by the Health Research Ethics Committee at Stellenbosch University and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guideline for Research.

WHAT IS THIS RESEARCH STUDY ALL ABOUT?

The purpose is to explore and describe the experiences of adolescents living with HIV infection about the health facilities physical and social environment, their interaction with health care workers and identify their expectation regarding health care services.

The study will be conducted at Ngoajane health facility and Baylor health facility. The number of participants will be determined by in depth rich information gained. You will be interviewed about your experiences regarding health services in this health facility. The interview will take approximately 40 to 60 minutes.

Your identity will not be revealed while the study is being conducted and when the study is reported or published. The interview will be conducted by researcher and will be audio taped; the interviews will not be shared with any person without your permission

WHY HAVE YOU BEEN INVITED TO PARTICIPATE?

You have been invited in the study because you are considered as an individual with in depth rich knowledge of the situation.

WILL YOU BENEFIT FROM TAKING PART IN THIS RESEARCH?

There is no direct benefit to you from being in this study. However, your participation may help others in the future as a result of knowledge gained from research.

ARE THERE ANY RISKS INVOLVED IN YOUR TAKING PART IN THIS RESEARCH?

The interview might cause fatigue. You can rest/take a break at any time. You may feel emotional or upset when answering some of the questions. You can tell the interviewer at any time if he/she wants to take a break or stop the interview.

IF YOU DO NOT AGREE TO TAKE PART, WHAT ALTERNATIVES YOU HAVE?

Your participation is entirely voluntary, and you are free to decline to participate. if you say no, this will not affect you negatively in any way whatsoever. you are also free to withdraw from the study at any point, even if you do agree to take part.

WILL YOU BE PAID TO TAKE PART IN THIS STUDY AND ARE THERE ANY COSTS INVOLVED?

You will not be paid to take part in the study, but your transport will be covered if you incur any for attending the interview and will be provided with some refreshment during the interview.

IS THERE ANYTHING ELSE THAT YOU SHOULD KNOW OR DO?

You are free to inform your parents that you are participating in this study. You can contact the Health Research Ethics Committee at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by the researcher.

You will receive a copy of this information and consent form for your own records.

Declaration by participant

By signing below, I …….. agree to take part in a research study entitled: Experiences of adolescents living with HIV infection attending health services in Botha-Bothe District Lesotho.

I declare that:

I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.

I have had a chance to ask questions and all my questions have been adequately answered.

I understand that taking part in this study is voluntary and I have not been pressurised to take part.

I may choose to leave the study at any time and will not be penalised or prejudiced in any way.

I understand that the interview will be audio taped and I agree that I am comfortable.

Signed at (*place*) .....……. on (*date*) ……..…….

_____ _____

Signature of participant **Signature of witness**

Declaration by investigator

I *(name)* ……..…… declare that:

I explained the information in this document to …….

I encouraged him/her to ask questions and took adequate time to answer them.

I am satisfied that he/she adequately understands all aspects of the research, as discussed above.

I did not use an interpreter.

Signed at (*place*) .....…..…… on (*date*) ……..…….

_____ _____

Signature of investigator Signature of witness

_____ _____

Signature of participant Signature of witness

Declaration by investigator

I *(name)* ……..…… declare that:

I explained the information in this document to …….

I encouraged him/her to ask questions and took adequate time to answer them.

I am satisfied that he/she adequately understands all aspects of the research, as discussed above

I did not use an interpreter.

Signed at (*place*) .....…..…… on (*date*) ……..…….

_____ _____

Signature of investigator Signature of witness

PARENTAL PERMISSION FORM FOR CHILD'S RESEARCH PARTICIPATION

TITLE OF THE RESEARCH PROJECT: Experiences of adolescents living with HIV and attending healthcare services in Botha-Bothe District, Lesotho.

REFERENCE NUMBER: 21362610

PRINCIPAL INVESTIGATOR: Mamoferefere Tatapa Zim Mabandla

ADDRESS: Lipelaneng Ha kamoho
P.O. Box 32
Botha-Bothe, Lesotho
CONTACT NUMBER: +26659184558

Your child is being asked to take part in a research study. This form has important information about the reason for doing this study, what we will ask your child to do, and the way we would like to use information about your child if you choose to allow your child to participate in the study.

This study has been approved by the Health Research Ethics Committee at Stellenbosch University and will be conducted according to the ethical guidelines and principles of the International Declaration of Helsinki, the South African Guidelines for Good Clinical Practice, and the Medical Research Council (MRC) Ethical Guidelines for Research.

WHAT IS THIS RESEARCH PROJECT ALL ABOUT?

The project will explore and describe the experiences of adolescents living with HIV infection in respect of the healthcare facility's physical and social environment, their interaction with healthcare workers, and will also identify adolescents' expectation of healthcare services. Your child will be interviewed about his or her experiences regarding healthcare services in the health facility. The interview will take 40 to 60 minutes. The study will be conducted at Ngoajane Health Facility and Baylor Health Facility. The number of participants will be determined by in-depth, rich information gained.

Your child's identity will not be revealed while the study is being conducted and when the study is reported or published. The interview will be conducted by the researcher and will be audiotaped; the interviews will not be shared with any person without your permission.

WILL YOUR CHILD BENEFIT FROM TAKING PART IN THIS RESEARCH?

There is no direct benefit to your child from being part of this study. However, his or her participation may help others in the future as a result of the knowledge gained from the research.

ARE THERE ANY RISKS INVOLVED IN TAKING PART IN THE RESEARCH?

The interview might cause your child to be fatigued. Your child can rest/take a break at any time. Your child may feel emotional or upset when answering some of the questions. Your child can tell the interviewer at any time, if he/she wants to take a break or to stop the interview.

WILL YOUR CHILD BE PAID TO TAKE PART IN THE STUDY, AND ARE THERE ANY COSTS INVOLVED?

Participation in the study will involve no cost for you or your child. Your child will not be paid for participation in the study, refreshments will be provided, and transport costs will be covered if your child incurs any for each study visit.

IS THERE ANYTHING ELSE THAT YOU SHOULD KNOW OR DO?

You can contact the Health Research Ethics Committee on 021-938 9207, if you have any concerns or complaints that have not been adequately addressed by the researcher.

Parental Permission for Child's Participation in the Research

I have read this form and the research study has been explained to me. I have been given the opportunity to ask questions, and my questions have been answered. If I have additional questions, I have been told who to contact. I give permission for my child to participate in the research study described above and will receive a copy of this Parental Permission form after I have signed it.

Declaration by parent/authorising guardian

By signing below, I …….. agree that my child will take part in a research study entitled: Experiences of adolescents living with HIV infection, and attending healthcare services in Botha-Bothe District, Lesotho.

I declare that:

I have read or had read to me this information and consent form, and it is written in a language with which I am fluent and comfortable.

I have had a chance to ask questions and all my questions have been adequately answered.

I understand that taking part in this study is voluntary, and I have not been pressurised to agree to my child taking part.

My child may choose to leave the study at any time and will not be penalised or prejudiced in any way.

I understand that the interview will be audiotaped, and I agree that I am comfortable with this.

Signed at (*place*) .....…..…… on (*date*) ……...…….

_____ _____

Signature of Participant Signature of Witness

Declaration by the investigator

I *(name)* ……..…… declare that:

I explained the information in this document to ……..

I encouraged him/her to ask questions and took adequate time to answer them.

I am satisfied that he/she adequately understands all aspects of the research, as discussed above.

I did not use an interpreter.

Signed at (*place*) .....…..…… on (*date*) ……...…….

_____ _____

Signature of investigator Signature of witness

APPENDIX 4: Interview guide

Section A

Name of facility:

Age:

Gender:

How long have you been attending health services in this facility?

Section B

1. Tell me more about yourself? How long have you been accessing services from this facility?

   Tell me more about the health services that you use at this facility?

Probe: What types of services do you receive in this facility?

: How do you receive them?

: How are these services provided?

2. Tell me more about your feelings about the facility's physical environment?

Probes: Are educational materials available at the facility?

: How does it look on the outside and inside?

: Are there spaces to relax? Are there spaces for entertainment?

: Do they play music? Can you play computer games?

3. Would you please relate your experiences about the facility's social environment?

Probes: Do other adolescents like coming here?

: How do health care workers communicate with you?

: Are the health care workers considerate? Are they easy to relate to?

4. Tell me more about what you would like this facility to be like?

Probes: Are there any characteristics you think should be added to make services friendly?

: How can service provision be made convenient?

APPENDIX 5: EXTRACT OF TRANSCRIBED INTERVIEW

Interview Number 5

Researcher: Good day

Participant: Good day

Researcher: How old are you?

Participant: 15 years

Researcher: you are 15 years

Participant: Yes

Researcher: Where do you access services?

Participant: I access services at----------

Researcher: How long have you been accessing services here?

Participant: I started last year, beginning of the year.

Researcher: You started last year were you taking treatment regularly or you had some break in between?

Participant: there was a time when I was not coming to collect drugs regularly.

Researcher: What were the reasons of not coming to collect drugs regularly?

Participant: When I was staying at the boarding school, people whom I was staying with did not have knowledge about drugs

Researcher: Yes, then?

Participant: Then I was transferred from that facility I was previously taking drugs to this present one, then I went to stay with my grandmother; while I was staying with my grandmother I took my medication properly. There was a time when we had misunderstanding, then I stopped taking my medication and then I was taken to a foster home, where I am staying and now, I am taking my medication properly.

Researcher: you did not take your medication because you grandmother was not supporting or encouraging you to take your medication?

Participant: No, she expelled me from her family, so I left my medication there.

Researcher: Grandmother expelled you from her family?

Participant: Yes, then I left my medication there.

Researcher: where were you staying?

Participant: I was staying at the street; my shelter was an old non-functioning vehicles.

Researcher: you stayed at old vehicle, not in someone's family?

Participant: Yes

Researcher: what were you eating there?

Participant: I was not eating

Researcher: you said the first time you stopped taking your medication because you were staying at the boarding school, the people there did not have knowledge about drugs, who did not have knowledge about drugs, caretakers or who?

Participant: Caretakers

Researcher: Caretakers were the one who did not understand the importance of medication.

Participant: Yes

Researcher: What about you did you have interest to take medication or you had challenge of taking them because you were staying with people who do not understand?

Participant: I did not have challenge of taking them.

Researcher: It was just that you did not have support?

Participant: yes

Researcher: OK tell me more about yourself? I told you about myself, I told you my name, and that I am continuing my education.

Participant: My name is----------I stay at foster home; I am 15 years am in form A at---- high school, I am a student, I take medication at---

Researcher: You said it has been how long you have taking medication from this facility?

Participant: This is the second year.

Researcher: This is the second year taking drugs?

Participant: Yes

Researcher: You come here to collect drugs for what?

Participant: My drugs for infection

Researcher: What infection?

Participant: HIV

Researcher: You are living with HIV infection?

Participant: Yes

Researcher: You are taking drug that suppress HIV?

Participant: Yes

Researcher: Oh!! Its two years now taking your medication. You stopped taking medication because you were staying at boarding school; people whom you were staying with did not have knowledge and understanding about your medication. Second time you stopped because you had misunderstanding with your grandmother, you were not staying at home.

Participant: yes

Researcher: you were staying at old, none functioning vehicles or let me call it at the street.

Participant: yes

Researcher: Then you were not able to take medication because you left them at your grandmother's place.

Participant: Yes

Researcher: This time are you taking them well?

Participant: Yes

Researcher: Tell me more about your feelings regarding environment?

Participant: It is a clean environment.

Researcher: It is clean, again?

Participant: I can see that only

Researcher: It is clean, how does it look inside and outside?

Participant: It looks nicely

Researcher: When you say nicely what do you mean because the word nicely is broad? When you say something is nice what should I expect according to your explanation?

Participant:...(silence)

Researcher: As an adolescent what do you mean when you say something is nice?

Participant:....(silence) I mean there are no bad things.

Researcher: You mean there are no bad things?

Participant: It is an attractive garden.

Researcher: It is an attractive garden?

Participant: Yes

Researcher: When you have come for services are there educational materials to read while waiting for services?

Participant: No

Researcher: They are not there? Is there any music played while waiting for services?

Participant: No

Researcher: No music is played, is there any space to relax when you have come to collect drugs, you just go there and relax?

Participant: No

Researcher: There is no space to relax, is there space for entertainment?

Participant: We entertain ourselves at this time only.

Researcher: At this time only?

Participant: When we have come to teen club.

Researcher: You entertain yourself only when you have come to teen club, when you come to collect treatment there is no time for entertainment?

Participant: Yes

Researcher: Are there computer games at the facility?

Participant: No

Researcher: They are not there?

Participant: Yes

Researcher: As you have said that you took drugs and stopped them according to reasons you have given, just relax this is conversation will not be shared, how are healthcare workers communicate with you?

Participant: They communicate with us nicely.

Researcher: Are they considerate?

Participant: Yes

Researcher: When you say they are considerate what do you mean?

Participant: I mean when we have come for services, they serve us nicely, they show us our mistakes if we have them.

Researcher: When you have come for services, they show you your mistakes?

Participant: Yes.

Researcher: You said how do they talk with you?

Participant: They talk to us nicely.

Researcher: They talk to you nicely, you said when you made mistakes, they show you them nicely?

Participant: Yes

Researcher: Can you voice out your opinions freely to them?

Participant: Yes

Researcher: How?

Participant: Silence

Researcher: Have I asked you difficult question?

Participant: Yes

Researcher: Do they consider other people's opinion?

Participant: Yes

Researcher: Do you ever voice out your opinion?

Participant: yes

Researcher: When you have voice out your opinion do, they listen?

Participant: yes

Researcher: Give the example on when you voiced out your opinion?

Participant: I voiced out my opinion while I was staying with my grandmother and my grandmother expelled me, they took initiative of finding a place for me to stay.

Researcher: You voice out your opinion to healthcare workers or your grandmother?

Participant: To them

Researcher: What did you talked about that made your grandmother angry?

Participant: I told them only when I was no longer staying with my grandmother.

Researcher: Then you were free to tell them that your grandmother had expelled you, you do not have place to stay, they take you to foster home, and they did not take you back to your grandmother?

Participant: yes

Researcher: Then you realized that they are people whom you can voice out your opinions freely?

Participant: Yes

Researcher: Looking at the facility that you access services you said is okay, what do you think which area should be improved?

Participant: here at the facility?

Researcher: Yes, to make it attractive.

Participant: I think there should be space to relax when we have come for services.

Researcher: There should be space to relax when you have come for services?

Participant: Yes

Researcher: Again?

Participant: Only

Researcher: Is the only thing that you would like to have?

Participant: Yes

Researcher: What can be done to provide services at your time? As an adolescent I would say it is conducive to come at the certain time, what can you say?

Participant:...(silence) I would say as an adolescent we would come Thursday morning at 8'oclock to 10'oclock.

Researcher: Then?

Participant: Then from there we go to different schools.

Researcher: According to you conducive time for you is Thursday only?

Participant: Thursday and Tuesday.

Researcher: Why those stipulated days?

Participant: Because those days.....because those days are better at school, I observed that not much is done.

Researcher: Thursday and Tuesday are appropriate for adolescents because school issues are not disturbed much? What you mean is that you wish provision of services should not affect school schedule?

Participant: Yes

Researcher: So that you can attend school?

Participant: Yes.

Researcher: What are you doing here on Saturday?

Participant: We have come for entertainment and to be taught about the importance of medication.

Researcher: Ok, you have come for entertainment and to be taught about medication?

Participant: Yes.

Researcher: You told me your name; you are attending school at---------- .You are living with HIV infection; you are taking medication from this facility, you said there was a time when you did not come to collect or use your medication, the reason being you were staying at boarding school, people whom you were living with did not have knowledge about your medication, so they failed to support you when you come for medication, then you stopped taking them; you came back and you were restarted on treatment later when you were staying with your grandmother; You stopped again taking medication and you did not come for services because you had misunderstanding?

Participant: Yes

Researcher: She expelled you from her family, you had to go and live in street, you stopped taking medication and stopped to come for services, is this what you said?

Participant: Yes

Researcher: we also talked about the environment you said the environment is clean is it so?

Participant: Yes

Researcher: Inside and outside there is no dirt?

Participant: Yes

Researcher: I also asked whether there are educational materials when you have come for services and you said they are not there; there is no music played; no space to relax, nor space for entertainment; no TV games or computer games, is what you have said.

Researcher: Do you want to add anything?

Participant: no

Researcher: just relax let's talk, because we want to hear any challenges you encounter when you have come for services, do you understand?

Participant: Yes

Researcher: I also asked you whether healthcare workers are considerate, you said they are considerate, and you can voice out your opinions freely?

Participant: yes

Researcher: you said you were able to voice out your opinions freely when your grandmother expelled you from your family, then healthcare workers took initiative to get foster home to stay; meaning that now where you are staying you are able to come to collect medication at scheduled time or you come whenever you like.

Participant: I come at scheduled time.

Researcher: You also said that conducive time for adolescent to come for services can be Tuesday and Thursday because on those days not much is done at school. When you come other days these affect school attendances, I am still saying what you have said?

Participant: Yes

Researcher: I also asked you what can be improved, and you said you would like to have space to relax. So far that is our conversation in summary. Is there anything to

add? Apart from that you did not get support from the family, that's why you came for services reluctantly, anything to add?

Participant: There is nothing to add?

Researcher: Apart from lack of support from the family that affected your attendance of services how do you feel about taking medication?

Participant: My feelings are that I am supposed to take medication for the sake of my life.

Researcher: you are supposed to take medication for the sake of your life?

Participant: Yes

Researcher: Even this time that you are scheduled for services it is still okay for you? Just relax and voice out your opinions.

Participant: Yes

Researcher: It is okay except that you would suggest coming on Tuesday or Thursday, as we have talked so far about things that contributed to your irregular attendance of services, is there anything you can add?

Participant: No

Researcher: When we are saying the family did not support you, boarding school there was no support which affected you to the extent that you did not take your medication properly what was happening exactly?

Participant: silence

Researcher: When you were at boarding school who was collecting treatment for you?

Participant: It was I; I came to collect medication.

Researcher: You collected medication?

Participant: When I arrive at boarding school, I kept my drugs then go to school.

Researcher: When it is the time to take them?

Participant: I would be called to come and take my medication, sometimes I just went and took them without being called. Sometimes when I have forgotten to take them and the time had passed, I would be given instruction not to take them because the stipulated time had passed.

Researcher: They told you not to take them because the time had passed?

Participant: Yes

Researcher: Then when you come to the facility you were told that you have not taken your medication properly?

Participant: Yes

Researcher: Then what happen if you did not take them properly?

Participant: Then I would be told to come with my parents, when I told my caretaker she did not come, and I just came alone.

Researcher: If you did not take your medication properly, you would be told to bring your parents and when you have told the caretaker did not come; you then continue to come alone. Even if she did not come you still had courage to come for services?

Participant: Yes

Researcher: How did the healthcare workers reacted to the situation when you came alone without caretaker?

Participant: They took initiative that we went with them to the boarding and they talked with the caretaker, then after that I was able to take my medication properly.

Researcher: meaning when it was said that you should bring caretaker, it takes us back where you said you were able to voice out your opinions to them, even though I did not come to collect medication as stipulated, I have the challenge of forgetting to take them and the caretaker would tell me not to take them when the stipulated time had passed.

Participant: Yes

Researcher: Then when I came to the facility, I usually told that I have not taken my medication properly and they took initiative to go to caretaker and talked to her?

Participant: yes

Researcher: Then later you took your medication properly, but later you had to leave boarding, why did you leave?

Participant: My uncle did not pay school fees and it was time for school to close because I was supposed to go home when school close. My uncle left without paying my school fees, then my grandmother and my aunt sent a message through my classmate that I should visit them when school close. When school close I went to my grandmother's place. I then stayed there.

Researcher: Your uncle was no longer paying school fees and when school closed you went to your grandmother?

Participant: Yes

Researcher: Until whereby there was misunderstanding, how was your grandmother when you were taking your medication, was she reminding you?

Participant: She was reminding me.

Researcher: She was reminding you; did you ever come with your grandmother to the facility? Did they discuss with her about your medication, not coming for services regularly?

Participant: Yes

Researcher: What happened after that?

Participant: After that I took my medication properly.

Researcher Until you had misunderstanding, then after this misunderstanding you did not come for treatment?

Participant: Yes

Researcher: You had misunderstanding with your grandmother, you left your grandmother's place, you stayed in the street at the old non-functioning vehicles as your shelter, and how did the healthcare workers knew that you are staying there?

Participant: I was brought by my former teacher at primary school I came here with her.

Researcher: Madam knew that you are not staying with your grandmother then she searched for you?

Participant: She is my grandmother's neighbour.

Researcher: Madam is your grandmother's neighbour?

Participant: Yes

Researcher: She knew that you had misunderstanding with your grandmother and you are not staying at home, she then looked for you, she found you, then brought you to the facility to report that you do not come for services, you do not take your medication because you are no longer staying at home?

Participant: yes

Researcher: They then took you to foster home?

Participant: Yes

Researcher: Is there anything you can tell me?

Participant: No

Researcher: That's all?

Participant: Yes

Researcher: Thank you for your time to talk to you about challenges that you face until you end up not coming to the services and not taking medication well, so that where there is need to improve health services, they should be improvement; tell me you said you were not given support at home and you end up not coming for

services or not taking medication well, now at school what is the situation? Is there any support?

Participant: It's there

Researcher: You are free that you take medication?

Participant: Yes

Researcher: Nothing unusual happens?

Participant: There is none because my friend also takes medication, we are always together.

Researcher: At school you found a friend who takes medication, then you feel free that you are like other people, then you must come for medication? Are they all?

Participant: Yes

Researcher: Thank you for your time, unless there is something you want to add. I still assure you that what we have been discussing is for educational purpose and for future improvement of services, they should not affect the way you are getting your services, there is no such a time that one day they will say that you said this to that lady. Thank you

APPENDIX 6: DECLARATIONS BY LANGUAGE AND TECHNICAL EDITORS

Busy Bee EDITING

115 Main Road, Cape Agulhas, Western Cape, South Africa
Cell: +27 72 244 4363
Email: info@busybeeediting.co.za / brendavanrensburg2@gmail.com
Website: www.busybeeediting.co.za

Proofreading and Editing Certificate

TO WHOM IT MAY CONCERN

This is to certify that we Brenda van Rensburg and Hugo Chandler the owners of the above company are both professional freelance proof-readers and editors. For the past twelve years we have been providing proofreading, editing, layout, syntax, spelling and grammar checks as well as typing and graphic design services to university students and to graduates for their theses, reports and dissertations, as well as to authors for their manuscripts. We will gladly provide any references if needs be.

We have completed the proofreading, editing, layout, syntax, spelling and grammar check on a Thesis for **MAMOFEREFERE ZIM TATAPA MABANDLA.**

Brenda van Rensburg
Brenda van Rensburg

Hugo Chandler
Hugo Chandler

Date: 4 November 2019