FACTORS INFLUENCING THE SELF-MANAGEMENT YOUTH LIVING WITH HIV IN LESOTHO

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DECLARATION

By submitting this thesis electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the sole author thereof (save to the extent explicitly otherwise stated), that reproduction and publication thereof by Stellenbosch University will not infringe any third-party rights and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

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ABSTRACT

Background: Many adolescents and youth live with the human immunodeficiency virus (HIV) worldwide. The HIV treatment goals and health outcomes of adolescents and youth living with HIV (YLWHIV) are lagging. One way to improve outcomes is through supporting YLWHIV to acquire self-management (SM) skills. Self-Management is a youth's ability to take control of their health and adopt good health practices. Although SM is associated with improved health outcomes, condition-specific, environmental, individual and family contextual factors influence SM. Knowledge of contextual factors influencing SM of YLWHIV in Lesotho could assist in tailoring SM support strategies.

Aim: The study aimed to describe the factors that influence SM of YLWHIV in Lesotho. The specific objectives were to determine the condition-specific, physical, and social environmental factors as well as the individual and family characteristics influencing SM of YLWHIV in Lesotho.

Methods: An exploratory-descriptive, cross-sectional quantitative research design was used. Youth living with HIV (n=184), aged 15-24, were conveniently sampled from two HIV treatment sites in Lesotho. The data were collected through a validated self-report questionnaire available in English and Sesotho. Data analysis was done using the Statistical Package of Social Sciences (SPSS) version 27 to obtain descriptive and inferential statistics. The Stellenbosch University Health Research Ethics Committee waived parental consent for adolescents younger than 18.

Results: Participants had high SM scores (mean 92.7%), which corresponded with their treatment outcomes. Almost all the participants (98.9%; n=181) indicated that they never missed a dose of their antiretroviral treatment (ART). All the participants (100%; n=183) had viral load values of less than 1000 copies/ml. Although SM scores were high, YLWHIV had lower item mean scores in relational and participatory components, which are crucial for their transitioning to adult care, negotiating condom use and accessing community services.

High SM scores in this sample could be attributed to **condition-specific factors**, including once-daily doses (100%; n=182) and a longer duration on treatment (81.4%; n=149) on ART for more than 10 years). Regarding the **physical and social**

environmental factors, participants had access to youth-friendly health services; 97.9% (n=179) were satisfied with the services. Regarding **individual and family factors**, participants were older (median age 22; IQR 4) and the majority had stable living conditions (61.7%; n=113) living with their current caregiver for more than 10 years). Individual strengths were associated with higher SM scores ($p<0.01$); mental health problems were associated with lower levels of SM ($p<0.05$).

Conclusion: The study supports the notion that uncomplicated treatment regimens, longer duration on treatment, access to adolescent-friendly services, and stable living conditions may lead to better SM. However, further exploration of factors influencing SM across various healthcare settings and with more diverse YLWHIV are needed to contextualise SM support interventions for YLWHIV, particularly those transitioning to adult care, to ensure meeting global targets.

Key words: Youth, adolescents, young people, HIV and AIDS, self-management

OPSOMMING

Agtergrond: Vele adolessente en jeugdiges wêreldwyd moet saamleef met die menslike immuniteitsgebreksvirus (MIV). MIV-behandelingsdoelwitte en gesondheidsuitkomste van adolessente en jeug wat met MIV leef (JMIVL) is agterblywend. Een manier om die uitkomste te verbeter, is om JMIVL met die verwerwing van selfbestuur (SB) te ondersteun. SB is ŉ jeugdige se vermoë om beheer oor hul gesondheid uit te oefen en om goeie gesondheidspraktyke aan te neem. Alhoewel SB met verbeterde gesondheidsuitkomste geassosieer word, is daar verskeie faktore wat SB beïnvloed. Hierdie faktore is toestand-spesifiek en sluit die omgewing asook die konteks van die individu en familie in. Kennis rondom die faktore wat die SB van JMIVL beïnvloed, kan gebruik word om SD-ondersteuningstrategieë vir JMIVL in Lesotho aan te pas.

Doelstelling: Hierdie studie het beoog om die faktore wat die SB van JMIVL beïnvloed, te beskryf. Die spesifieke doelwitte was om die toestand-spesifieke, fisiese, en sosiale omgewingsfaktore, asook die individuele en familie-kenmerke wat die SB van JMIVL in Lesotho beïnvloed, te bepaal.

Metodes: ŉ Verkennend-beskrywende, kwantitatiewe deursneestudie-ontwerp is gebruik. JMIVL (n=184), tussen die ouderdomme van 15 tot 24 jaar, is deur middel van ŉ geriefsteekproefneming by twee MIV-behandelingsplekke vir die navorsing gewerf. Die data is deur middel van ŉ gestaafde selfrapporteringsvraelys, beskikbaar in Engels en Sesotho, ingesamel. Die Statistiese Pakket van Sosiale Wetenskappe (SPSS) weergawe 27 is gebruik om die data-analise te doen ten einde beskrywende en afleibare statistieke te verkry. Die Universiteit van Stellenbosch se Gesondheidsnavorsing en etiekkomitee het ouerlike toestemming vir adolessente jonger as 18 opsygesit.

Resultate: Deelnemers het hoë SB-tellings gehad (gemiddeld 92.7%). Die telling stem ooreen met hul behandelingsuitkomste. Amper al die deelnemers (98.9%; n=181) het aangedui dat hulle nooit ŉ dosis van hulle antiretrovirale behandeling (ARB) gemis het nie. Al die deelnemers (100%; n=183) het virale ladingswaardes van minder as 1000 kopieë/ml gehad. Alhoewel die SB-tellings hoog was, het JMIVL laer gemiddelde tellings in die komponente van verhoudings en deelname gehad. Hierdie komponente is deurslaggewend vir hul oorgang na volwasse sorg, onderhandeling van kondoomgebruik en toegang to gemeenskapsdienste.

Hoë SB-tellings in hierdie groep kan aan **toestand-spesifieke faktore** toegeskryf word, insluitend dat dosisse slegs een maal per dag is (100%; n=182) en dat meeste van die deelnemers al vir ʼn langer tydperk op behandeling is (81.4%; n=149 op ARB vir meer as 10 jaar). Rakende die fisiese en sosiale omgewingsfaktore, het die navorsing aangedui dat deelnemers toegang tot jeug-vriendelik gesondheidsdienste het en dat 97.9% (n=179) tevrede was met die dienste. Rakende die individuele en familie faktore, is die deelnemers ouer jeugdiges (gemiddelde ouderdom van 22; IQR4) en meeste van hulle het stabiele lewensomstandighede (61.7%; n=113) bly al vir meer as 10 jaar saam met hulle huidige versorger). Individuele sterkpunte is geassosieer met hoër SD-tellings ($p<0.01$) en geestesgesondheidsprobleme is geassosieer met laer SD-vlakke ($p<0.05$).

Slotsom: Hierdie studie ondersteun die opvatting dat behandelingsvoorskrifte wat nie ingewikkeld is nie, ʼn langer behandelingstydperk, toegang tot adolessente-vriendelike dienste, en stabiele lewensomstandighede tot beter SB lei. Verdere navorsing is egter nodig om die faktore wat SB by verskeie gesondheidsorg-omgewings beïnvloed te ondersoek. Navorsing wat meer diverse JMIVL insluit is ook nodig om SB-ondersteunende intervensies vir JMIVL binne konteks te plaas, veral vir diegene wat oorgaan na volwasse sorg. Sodoende kan wêreld-doelwitte bereik word.

Sleutelwoorde: Jeugdiges, adolessente, jongmense, MIV en VIGS, self-bestuur

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ABBREVIATIONS

AdHIVSM	Adolescent HIV Self-Management Scale (AdHIVSM)
AIDS	Acquired Immune Deficiency Syndrome
ALWHIV	Adolescents living with HIV
ART	Antiretroviral Therapy
ARV	Antiretroviral
CI	Confidence Interval
HAART	Highly Active Antiretroviral Treatment
HREC	Health Research Ethics Committee
IFSMT	Individual and Family Self-Management Theory
LECSA	Lesotho Evangelical Church of Southern Africa
MoH	Ministry of Health
MTCT	Mother to child transmission
PEP	Post Exposure Prophylaxis
PLWHIV	People living with HIV
PrEP	Pre-exposure Prophylaxis
SDQ	Strengths and Difficulties Questionnaire
SM	Self-management
SPSS	Statistical Package for the Social Sciences
UNAIDS	Joint United Nations programme on HIV/AIDS
UNICEF	United Nations International Children’s Education Fund
VMMC	Voluntary Male Medical Circumcision
WHO	World Health Organisation
YLWHIV	Youth living with HIV

CHAPTER 1

FOUNDATION OF THE STUDY

1.1 Introduction

Adolescents and youth are among the majority of people living with HIV globally. In 2019 alone, 410 000 young people between the ages of 10 to 24 were newly infected with HIV. Among these, 150 000 were adolescents between the ages 10 and 19. (United Nations International Children's Education Fund (UNICEF), 2021:1) The regions with the highest numbers of HIV-positive adolescents and youth are sub-Saharan Africa and South Asia. Of the 1.6 million adolescents and youth living with HIV, about 1.5 million [970,000-2.0 million] (89%) live in sub-Saharan Africa (Joint United Nations programme on HIV/AIDS (UNAIDS), 2019:1). Due to this increasing rate of the HIV epidemic and poor health outcomes among youth, new interventions are needed to address their needs. The World Health Organisation (WHO) defines adolescence as the age from 10 to 19 years and distinguishes between early (10-14) and late (15-19) adolescence (WHO, 2014:2). 'Youth' generally refers to individuals between15 to 24 years of age (WHO, 2014:14).

Self-management (SM) refers to the behaviours that individuals must perform to live well with one or more lifelong conditions. The tasks or behaviours include having the confidence to deal with medical management, role management, and the emotional management of their condition (Sawin, 2017:17). Lifelong illnesses such as HIV/AIDS, cancer, epilepsy and, asthma affect youth in many ways during their transition to adulthood and adult care. Supporting them to develop independence and SM skills is, therefore, a key task of healthcare professionals (Sattoe, Bal, Roelofs, Bal, Miedema & Van Staa, 2015:705).

As much as there have been studies investigating factors that influence SM of youth living with HIV (YLWHIV), very little is known about the factors influencing SM in the Lesotho context. The focus of this study was, therefore, on investigating the factors that influence SM of YLWHIV in the context of Lesotho.

1.2 Rationale

Acquired Immune Deficiency Syndrome (AIDS) is one of the diseases that account for the highest morbidity and mortality among young people living with HIV in sub-Saharan Africa (Armstrong, Lorpenda, Caswell & Kihara, 2017:4). Lesotho has the second highest HIV prevalence in the world. Twenty-five percent (25%) of people, or one in four people, in the country are living with HIV (Help Lesotho, 2017:1; Government of Lesotho, 2016:ix). The population that accounts for the highest number of people living with HIV (PLWHIV) is between 15-49 years of age, which is the age that includes youth (Elizabeth Glaser Paediatric AIDS Foundation, 2017:1The majority of YLWHIV in Lesotho are females (UNAIDS, 2019:35).

The Lesotho government introduced antiretroviral therapy (ART) as an important strategy to combat HIV. The ART programme was rolled out in 2004 in the public sector (Government of Lesotho, 2017:42)To access key populations affected by HIV, such as adolescents, some facilities are implementing differentiated service delivery models where youth corners, which are based on adolescent-friendly services, have been established to provide a range of services. Youth corners are health facilities that are entirely established for young people and all health services are rendered in such ‘corners’ (Government of Lesotho, 2017:45; Pike, Celum & Gail-Bekker, 2020:1).

Lesotho has several strategies in place to prevent the spread of HIV and deaths due to HIV-related illnesses. These include behavioural change methods, condom use, HIV education awareness, voluntary male medical circumcision (VMMC), pre-exposure prophylaxis (PrEP), post exposure prophylaxis (PEP), and the test and treat strategy (Government of Lesotho, 2017:46). However, despite these strategies, the mortality rate among YLWHIV doubled between the years 2000 and 2016. There may be multiple reasons for the high mortality rate. The YLWHIV have higher lost to follow-up rates and are less adherent to ART when compared to adults (Government of Lesotho, 2017:46). Lowenthal, Bakeera-Kitaka, Marukutira, Chapman, Goldrath and Ferrand (2014:16) also reiterate that adolescents and youth have challenges with adherence to ART.

Globally and within African settings, YLWHIV face various challenges that may compromise their ability to self-manage their chronic illness. There is still limited evidence regarding SM in adolescents where it was discovered that YLWHIV are not skilful enough to take their treatment as prescribed (Denison, Banda, Dennis, Packer, Nyambe, et al. 2015:1). Other authors purport that youth who come from a low resource setting may encounter problems that pertain to the contextual, developmental and cultural environment, which will affect their SM (Sharer & Fullem, 2012:13). The increased mortality and poor treatment outcomes amongst YLWHIV are a cause of concern and hence the need to investigate the factors influencing SM among YLWHIV.

SM skills and abilities lead to positive behaviours such as taking treatment, attending appointments, and refraining from risky behaviours; this, in turn, leads to better health outcomes and wellbeing (Sawin, 2017:173). Several systematic reviews found that SM interventions improve the health-related outcomes of PLWHIV and YLWHIV (Aantjies, Ramerman & Bunders, 2014:186; Milliard, Elliot & Girdler, 2013:104; Sattoe et al., 2015:705). Although better SM skills are associated with good health, both SM skills and SM outcomes are directly affected by several contextual risk and protective factors. Understanding these factors is key to developing interventions to support youth with SM and improving outcomes (Sawin, 2017:172). These contextual factors have not yet been explored in Lesotho.

According to the Individual and Family Self-Management Theory (IFSMT) of Ryan and Sawin (Ryan & Sawin, 2009; Sawin, 2017:172), the contextual factors that influence SM are: i) condition-specific; ii) the physical and social environments; and iii) individual and family characteristics. Sharer and Fullem (2012:12) report similar factors influencing SM in YLWHIV. They categorised these factors as individual, environmental and facility or clinical. An overview of the contextual factors is provided in Table 1.1. A detailed discussion is provided in chapter 2.

Table 1.1: Contextual factors influencing self-management in YLWHIV (Sawin, 2017; Lowenthal et al., 2014; Modi et al., 2012;Sharer & Fullem, 2012)

Condition-specific factors	Physical and social environment	Individual and family characteristics
• Type of medication/regimen • Frequency of treatment • Ill or stable	• Access to healthcare facilities • Transportation • Adolescent-friendly facilities/care	• Age of adolescent • Psychological strengths and difficulties • Health literacy • Family structure and functioning

1.3 Problem statement

Lesotho is a very small country but is the second hardest hit by the HIV epidemic globally. Despite the HIV prevention and management strategies already stipulated, YLWHIV still have poor health outcomes, which include poor retention in care and a high mortality rate (Government of Lesotho, 2017:46). Viral suppression rates among the YLWHIV globally and in Lesotho are a concern (Low, Thin, Davia et al., 2019:2). SM has been associated with better adherence and viral suppression rates amongst adolescents (Crowley, Van der Merwe, Kidd & Skinner, 2020:21), but it is influenced by various contextual factors (Sawin, 2017:172).

SM strategies may assist in improving outcomes, but better understanding of contextual factors will help to inform interventions to the specific context of Lesotho. The intention of this study was, therefore, to investigate the factors influencing SM in YLWHIV as the contextual factors have not been explored in Lesotho.

1.4 Research question

What are the factors that influence the SM of YLWHIV in Lesotho?

1.5 Research aim

The aim of this research was to describe the factors that influence the SM of YLWHIV in Lesotho.

1.6 Research objectives

The objectives of this research were to

- Establish the condition-specific factors influencing SM of YLWHIV in Lesotho.
- Ascertain the physical and social environmental factors influencing SM of YLWHIV in Lesotho.
- Determine the individual and family characteristics influencing SM of YLWHIV in Lesotho.

1.7 Conceptual framework

A conceptual framework elucidates the typical sequence of an occurrence under study (Adom, Hussein & Agyem, 2018:437). The conceptual framework aims to outline the different factors that are assumed to influence SM. This framework indicates the relationship between the different factors within the context and how this influences SM, as stipulated in the IFSMT created by Ryan and Sawin (2009). It is further postulated that SM skills and abilities will lead to SM behaviours such as adherence to treatment, which in turn leads to positive health outcomes.

Although there are many contextual factors that may influence SM, the researcher decided to focus on the factors depicted in the framework (Figure 1.1).

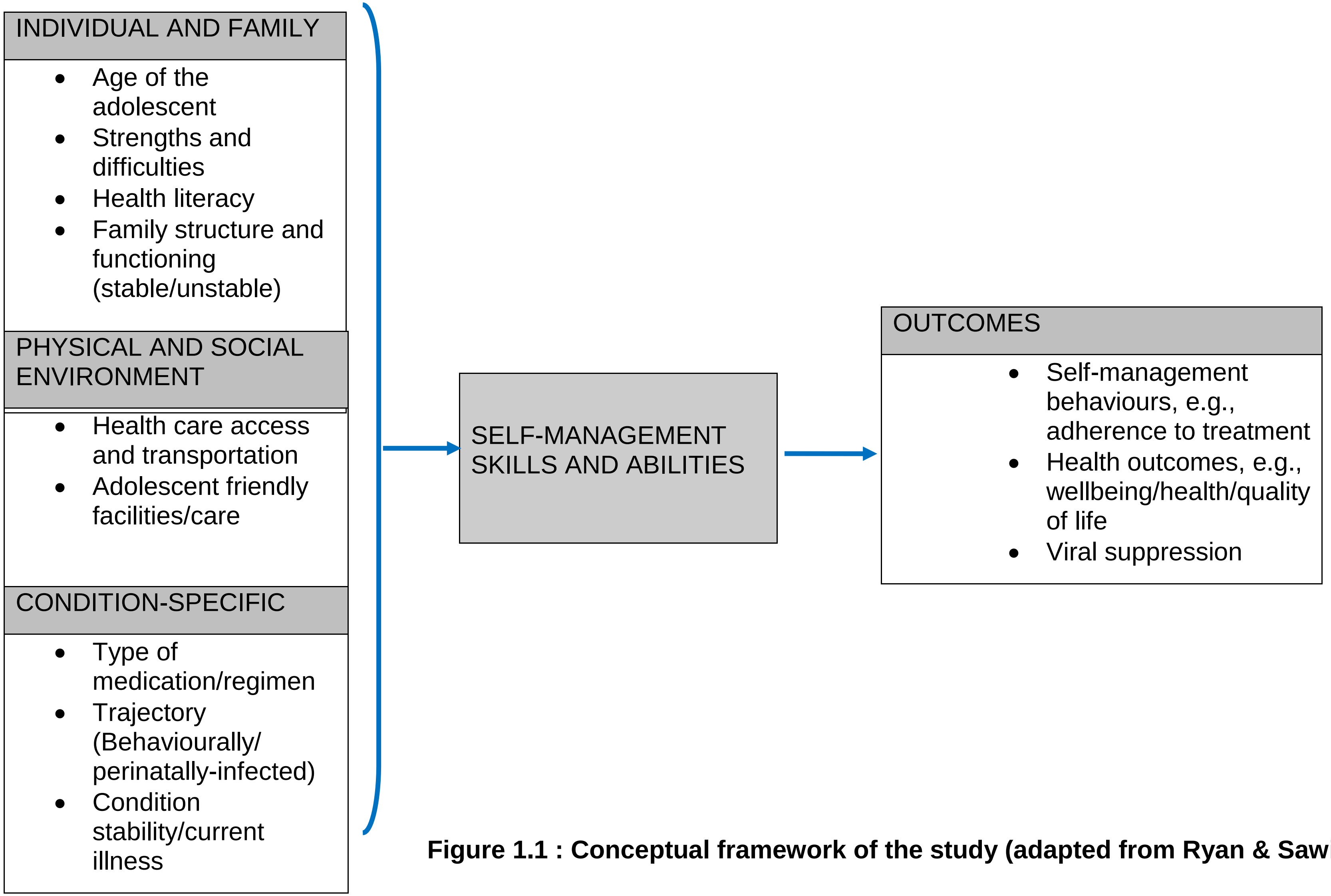


Figure 1.1 : Conceptual framework of the study (adapted from Ryan & Sawin, 2009)

1.8 Research methodology

The methodology will be briefly discussed in this chapter while a detailed overview will be discussed in chapter three.

1.8.1 Research design

This study utilised an exploratory-descriptive, cross sectional quantitative research design. This design was chosen because it is appropriate in describing phenomena at a fixed point in time (Polit & Beck 2017:206). Accordingly, the researcher wanted to describe the factors that influence SM.

1.8.2 Study setting

The study was conducted at the youth corner at Scott Hospital Morija Lesotho and at the ART corner of one of the clinics (health centres) that Scott Hospital supervises. Morija is a town in the Maseru District. Matelile is about 15 kilometers from Morija.

1.8.3 Population and sampling

In this study, the population was youth between the ages of 15-24 who are living with HIV, are aware of their status, and are on ART. One-hundred-and-eighty-four (n=184) participants were conveniently selected at the two health facilities over a period of three months. Of the 184 participants, 94 of them were recruited at Scott Hospital, while 90 of them were recruited from Matelile Health Centre.

1.8.4 Data collection

After approval to conduct the study by the Health Research Ethics Committee (HREC) of Stellenbosch University and the Ministry of Health Lesotho, the researcher wrote a request letter to the medical superintendent of Scott Hospital, who is also responsible for Matelile Health Centre, for permission to conduct the study. The data was collected using self-completion questionnaires measuring contextual factors and SM. The questionnaires were available in English and the local language, Sesotho. The data were collected from the 15th of November 2020 to the 15th of January 2021.

1.8.5 Pilot study

A pilot study was conducted to determine the feasibility of the main study. The researcher recruited the first 10 readily available participants from Scott Hospital and eight from Matelile Health Centre. The results of the pilot study are not included in the main study.

1.8.6 Validity and reliability

Validity and reliability were ensured by making use of established questionnaires that reported good reliability and validity measures and have been used in an African setting (Crowley, 2018:602).

1.8.7 Data analysis

The data from questionnaires were entered into the Statistical Programme for the Social Sciences (SPSS, version 27). After cleaning the data, descriptive and inferential statistics used to analyse the data with the assistance of a biostatistician from Stellenbosch University.

1.9 Ethical considerations

To ensure that ethical principles have been taken into consideration, the proposal was submitted to the Stellenbosch University HREC (S/20/06/139) and the Ministry of Health Lesotho for approval. The ethical principles followed in this study are the principles of beneficence, right to self-determination, right to privacy, right to confidentiality and anonymity, and the right to protection from discomfort and harm.

1.9.1 Informed consent

An informed consent form was issued to participants with the mental ability to consent to participate. Mental capacity was assessed by the researcher by determining if they understood the information provided. In the context of Lesotho, people younger than 18 years are considered too young to consent for research on their own. However, the HREC waived parental consent for participants who were younger than 18 years (15-17). The researcher ensured that all participants were provided with an informed consent form in the language of their choice (Appendix 3). The researcher also provided an information letter for participants younger than 18 years to take home (Appendix 3), so that parents could contact the researcher if they have questions. The researcher and fieldworker were present to explain anything to the participants that they did not understand. The languages used were Sesotho and English.

1.9.2 Right to self-determination

Participants were fully informed that participation was entirely voluntary and that they could withdraw from participating at any time. They were assured that there will be no repercussions or denial of services for refusing or withdrawing from participation in the study.

1.9.3 Right to confidentiality and anonymity

The principle of confidentiality and anonymity was achieved as the participants did not include their names on the questionnaires and no participants' and facilities' names were used. Completed questionnaires are stored in a lockable cabinet in the researcher's office that has limited access. All electronic data are stored on a computer secured with passwords that are only known by the researcher. To avoid the loss of data, the researcher ensured availability of a backup system. An external hard drive, secured with a password, is used to store the data. Informed consent forms are stored in the researcher's office, in the lockable cabinets. As mentioned, the office has limited access. Only the researcher, fieldworker, supervisor and the statistician who assisted in data analysis had access to the data.

1.9.4 Right to protection from discomfort and harm

In this study the participants did not incur any costs, as they were recruited on their already scheduled follow-up dates. The researcher, however, compensated the participants for their time spent while completing the questionnaire by providing them with refreshments that cost R20 per person.

1.10 Operational definitions

Youth: Youth is a person between the ages of 10-24 years (Egpaf, 2017: viii)

Self-management (SM): Behaviours in which people engage to promote their functionality and improve their health outcomes if they have a chronic illness (Sawin, 2017:171). In this study, SM was measured using the adolescent HIV self-management scale (AdHIVSM), which has been developed in South Africa and has been proven to be valid and reliable (Crowley, 2018: 602).

Youth health corners: These are adolescent and youth-friendly health services, established by the Ministry of Health, where young people are attended to by young healthcare workers with whom they feel more comfortable (Egpaf, 2017: vii).

Antiretroviral Therapy (ART): According to the WHO (2021:9), standard ART consists of the combination of antiretroviral (ARV) drugs to maximally suppress the HIV virus and stop the progression of HIV disease.

Contextual factors: The contextual risk and protective factors are factors that influence SM and they include (i) condition-specific factors; (ii) the physical and social environment; and (iii) individual and family characteristics (Ryan & Sawin, 2009:4).

1.11 Duration of the study

Ethics approval for this study was obtained in August 2020. The pilot study was conducted from 18 September to the 1st of October 2020. Data collection for the main study was done in mid-November, December 2020 and January 2021. Data analysis was performed in March 2021. The final thesis was submitted in December 2021.

1.12 Chapter outline

Chapter 1: Foundation of the study

This chapter contains an overview of the study background, research problem, and a summary of the research methodology.

Chapter 2: Literature review

This chapter contains an overview of the literature about the factors influencing SM. The chapter was organised to articulate the various factors influencing YLWHIV's SM.

Chapter 3: Research methodology

In this chapter, the research design, study setting, population and sampling, data collection, pilot study, data analysis, and ethical considerations are discussed in detail.

Chapter 4: Results

The results of the study are presented in chapter four.

Chapter 5: Discussion, conclusions and recommendations

This chapter includes a detailed discussion of the study findings, conclusion, and recommendations.

1.13 Significance of the study

In Lesotho, there has not been studies conducted on the SM of YLWHIV. The study assists to identify factors that influence SM and makes appropriate recommendations for SM support as better SM has been associated with better treatment and health outcomes (Crowley et al., 2020).

The researcher investigated contextual risk factors that could contribute to poor SM in order to adopt early therapies. . The research6er made recommendations about how healthcare workers can better monitor and support SM behaviours in youth.
There are limited programmes in the country that support adolescent SM. Therefore, the recommendations of the study will assist in guiding the establishment of such programmes. The results of the study will be disseminated to the appropriate offices so that YLWHIV can be assisted to improve their SM skills.

1.14 Conclusion

This study aimed to identify the factors that influence SM amongst YLWHIV in Lesotho. The motivation behind this study is to determine the contextual factors that influence SM in YLWHIV in Lesotho, so that, where possible, appropriate interventions can be implemented to improve SM. The next chapter includes the discussion of the literature about the SM of YLWHIV.

CHAPTER 2

LITERATURE REVIEW

2.1 Introduction

In chapter one, the introduction, the background, problem statement, research aim, research objectives, methodology and ethical principles were described. In this chapter, the literature that provides a background to the factors influencing self-management (SM) in youth living with HIV (YLWHIV) will be discussed in detail as delineated by the different authors. The purpose of the literature review was to identify gaps in knowledge and unresolved problems that could be addressed by this study.

The literature is organised to articulate the different factors influencing SM of YLWHIV in Lesotho. The literature review is arranged according to the following topics: global and national trends of HIV among the youth; challenges related to treatment and care of YLWHIV; SM as a strategy to empower people living with chronic conditions; SM of YLWH; and the factors influencing SM, including condition-specific factors, physical and environment factors, and the individual and family characteristics.

2.2 Electing and reviewing the literature

The researcher searched for relevant literature by using databases such as PubMed, Ebscohost, and Google Scholar. Key words and their Medical subject headings (MesH) terms encompassed:

- Population: (youth OR young people OR adolescents) AND (HIV OR AIDS)
- Issue: self-management OR self-care OR adherence
- Outcomes: quality of life OR development OR health outcomes

Studies that reported on SM and HIV were reviewed. Both quantitative and qualitative studies were included. Over 100 sources of information including articles, guidelines, books, and statistical reports were accessed and reviewed. The researcher opted to include the most relevant articles that were published within the last 10 years. Senile literature was also included where current literature was not accessed.

2.3 Global and national trends of HIV among the youth

AIDS is a serious public health problem. Regrettably, the target of ending AIDS by 2020 is proving difficult to achieve, as new infections among teens and youth continue to increase despite efforts to combat the epidemic (Khalifa, Stover, Mahy, Idele, Porth & Lwamba, 2019:3).

Adolescents and young people are becoming a larger proportion of HIV-positive people around the world. In 2020, 410 000 [194 000-690 000] youth aged 10 to 24 were newly infected with HIV, according to the World Health Organisation (UNICEF, 2021:2). Globally, approximately 1.7 million [1.1 million-2.4 million] adolescents aged 10 to 19 were living with HIV. Adolescents account for approximately 5% of all people living with HIV (PLWHIV) and comprise 10% of new HIV infections. Sub-Saharan Africa is home to 1.5 million [1.0 million-2.1 million] people (88%) of the world's population of people who live with HIV and nearly 90% of all children and adolescents living with HIV come from sub-Saharan Africa (UNICEF, 2021:2).

2.3.1 Young people and HIV in Lesotho

Young people are affected significantly by the HIV epidemic in Lesotho as the prevalence has increased among young women since 2009 when it was 10.5%, although it has remained stable among young men. The Lesotho Demographic Health Survey conducted in 2014, found that 13% of young women (aged 15-24) and 6% of young men in the same age group were living with HIV (Government of Lesotho, 2017:4).

Lesotho has made deliberate progress in ensuring that the high mortality rate among YLWHIV is reduced by increasing efforts to provide adequate youth-oriented support and services across the country (Government of Lesotho, 2017:5). There are also efforts to reduce the risks to young people acquiring HIV horizontally. Some of the strategies include the social and behaviour change Communication Strategy for Sexual and Reproductive Health rights and HIV in Lesotho. This strategy is intended to identify behavioural, socio-cultural, and structural factors as critical determinants of HIV risk in youth. The strategy, therefore, promotes the reduction of HIV infection by strengthening HIV communication through parents and caregivers of adolescents, including those in orphanages, peers of adolescents, youth clubs, and peer educators. These platforms are used to discuss HIV issues comprehensively and freely (Government of Lesotho, 2020:24).

Despite these interventions, there is still a certain proportion of young people who lack comprehensive knowledge about HIV and AIDS as well as those who still engage in risky sexual behaviours for various reasons. These reasons include, among others, pressure from friends and curiosity (Kolawole, Shola, Oyeyemi & Adebayo, 2014:8). For example, a national survey that was conducted between 2016 and 2017 to determine the country’s response towards HIV found that 6% of young men and 12% of young women reported engaging in sex for the first time before the age of 15 (Lesotho Population-Based HIV Impact Assessment 2017:5).

In Lesotho, 8% of young women (age 15-19) have admitted to sexual intercourse with a man 10 or more years older. This increases the risk to young women acquiring HIV as the sexually experienced older partner is more likely to be living with HIV than their younger counterparts (Avert, 2020:20).

Among other methods of HIV transmission, vertical transmission which is transmission of the HIV virus from the mother to the unborn baby in the perinatal and postnatal periods, also contributes to the increasing number of new HIV infections amongst youth. Children who have acquired HIV through vertical transmission and due to the availability and access to antiretroviral treatment from a young age, have grown up to be youth. The HIV mother-to-child transmission rate in Lesotho is at 5.9% (Avert, 2020:7). HIV prevalence and incidence rates remain a concern globally and in Lesotho. Further to this, YLWHIV may experience several challenges related to their treatment.

2.4 Challenges related to the treatment and care of YLWHIV

YLWHIV experiences challenges such as poor treatment outcomes as well as individual and environmental challenges. Each of these topics will be discussed in separate sub-headings.

2.4.1 Poor treatment outcomes

In a study conducted in South Africa, YLWHIV was found to have the lowest rates of HIV treatment retention in care and ART adherence. As a result, this age group has an increased risk of virological failure and they are more likely to experience increased morbidity and mortality (Cluver, Pantelic, Toska, Orkin, Casale, Bungane & Sherr, 2018:4. In the sub-Saharan region, 36 percent of HIV infections are young people, especially young girls and women aged 15 years and above. HIV has now become the primary cause of death amongst adolescents (Khalifa et al., 2019:2).

In a systematic review and meta-analysis of adherence amongst adolescents living with HIV, the lowest average ART adherence was in North America [53% (95% Confidence Interval (CI) 46-59], Europe [62% (95% CI 51-73)] and South America [63% (95% CI 47-77)]. The average ART adherence levels were higher in Africa [84% (95% CI 79-89)] and Asia [84% (95% CI 77-91)] (Kim, Gerver, Fildler & Ward, 2014:1950). Although adherence levels are higher in Africa, it is still suboptimal.

Challenges that impact poor treatment outcomes amongst YLWHIV include poor medication adherence, prevention of HIV transmission, management of HIV stigma, and a negative affective state. There is an intricate set of physical, emotional, and social difficulties that limit the ability of YLWHIV to care for themselves (Mutumba, Mugerwa, Musiime, Gautam, Nakyambadde, Matama & Stephenson, 2019:1). A study conducted in North America and Europe indicated that youth between the ages of 18 and 19 were particularly at risk of virological failure (Ritchwood, Malo, Jones, Metzger, Atujuna, Marcus, Conserve, Handler & Bekker, 2020:10).

2.4.2 Individual and environmental challenges of YLWHIV

Adolescents living with HIV also encounter significant clinical and psychosocial challenges, including continuous (life-long) healthcare needs and adherence to treatment. They experience social exclusion and discrimination when they disclose their HIV status to their friends, and this often leads to adverse consequences for their psychological wellbeing and possible disease progression (Nöstlinger,Bakeera Kitaka, Buyze, Loos & Buvé 2015:8). Failure to disclose one's status to friends because of the many challenges linked to HIV stigma potentially hampers YLWHIV's social support and bonding with peers (Xu, Munir, Kanabkaew & Le Coer, 2017:2).

YLWHIV who acquired HIV perinatally have been observed to be a group with specific challenges related to HIV treatment compared to their behaviourally infected peers (Armstrong et al., 2017:7). Adolescents who acquire HIV perinatally may have a more complicated clinical course of the disease, experience hardships at a tender age such as parental death and family instability, and encounter discrimination and trauma from disclosure of their HIV status. As they age, they also face the changes resulting from transitioning from paediatric to adult care, and the critical transition from dependence on caregivers to becoming independent and responsible citizens on their own, including the maintenance of ART adherence (Xu et al., 2017:2).

Youth may struggle to navigate a complex health system and are frequently not involved in decisions that affect their lives (Armstrong et al., 2017:17). Moreover, youth are a population that generally have busy lives. They are usually not informed about health issues, and some may live far from services. For others, the challenges may be aggravated by lack of resources including money for transport. (Armstrong et al., 2017:17).

2.5 Self-management as a strategy to empower people living with chronic condition

The advent of Highly Active Antiretroviral Treatment (HAART) enables HIV to be treated as a chronic manageable condition. There is scope to apply chronic care methods in the treatment of people who live with HIV (Aantjies et al., 2014:187). SM is defined as the activities that must be performed by someone with one or more chronic conditions to cope and live well (Sawin, 2017:170). According to Aantjies et al. (2014:187), SM is a tool that supports medical care so that the patient is an active partner with his/her professional healthcare providers. The support offered by health professionals includes continuous education and interventions to increase the skills and confidence of patients in managing their chronic condition.

For SM to be successful, health professionals undertake regular assessment of a patient's progress and provide support to enable him/her to solve problems and achieve improved health goals. Patient SM activities include treatment adherence, behavioural changes, disease monitoring and reporting, lifestyle adjustments, coping with emotional problems, and participating in treatment decisions. In essence, active patient involvement in healthcare management contributes to physical, mental and social wellbeing while promoting uncomplicated chronic illness management (Aantjies et al., 2014:186).

Ryan and Sawin (2009:217) have also observed that SM as a patient-centred approach to care is supported by empirical evidence demonstrating that the health outcomes of individuals and families who engage in SM improve. Moreover, SM is a process by which individuals and families use knowledge and beliefs to self-regulate skills and abilities as well as facilitate social interactions to achieve health-related outcomes (Sawin, 2017:171). The Individual and Family Self-Management Theory (IFSMT), described in Chapter 1, explains that SM occurs within the context of various condition-specific, individual and environmental factors.

According to Sattoe et al. (2015:705), the WHO's definition of health has also been redefined. Health means being able to adjust and execute SM tasks and abilities amid social, physical and emotional challenges. This is because living with a chronic condition is a lifetime process that requires a balance between medical and social needs. SM is therefore defined as a person's capability to deal with symptoms and the implications of living with a life-long illness.

Grady and Gough (2014:e25) point out that chronic illness is now the major focus of healthcare. Therefore, there is increased attention on approaches to manage chronic symptoms to maintain patient independence and quality of life over longer periods of time. Approaches to managing chronic illness are shifting from the traditional provider-patient relationship to a paradigm in which individuals with chronic conditions play a key role in guiding their care, in partnership with healthcare providers.

SM support reduces hospitalisations, emergency department use, and overall managed care costs (Bodenheimer, Wagner & Grumbach, 2002:13). Some patients may not be aware that taking an active role in managing their health can have a positive impact on how they feel and what they are able to do. Making good choices and sustaining healthy behaviours require patients to have new skills provided through a collaborative partnership that supports them in building confidence that can lead to new behaviours and affect outcomes. Effective SM may improve health outcomes and reduce health resource use (Farley, 2019:32).

Finally, SM improves health outcomes in chronic illness not only by improving adherence to the treatment plan but also by building the individual's capacity to navigate challenges and solve problems. Support for SM is a critical need among children and adolescents with (medically and/or socially) complex chronic conditions. SM must take the shape of a collaboration between the patient, family, and care providers in order for persons with chronic illness and their families to facilitate SM (Lozano & Houtrow, 2018:s233).

2.6 Self-management of YLWHIV

People with different chronic diseases have similar SM problems and disease-related tasks. Swedeman, Ingram, Rotherson-Borus (2010:1) indicate that, like other chronic diseases, HIV requires lifetime changes in physical health, psychological functioning, social relations, and adoption of disease-specific regimens. YLWH are no exception. They also fall in the category of people living with chronic conditions. It is important that they learn to take responsibility for the day-to-day management of their disease. If they become confident, knowledgeable patients who practice SM, they experience improved health and use fewer healthcare resources (Cutler,Crawford& Engleking,2018:359). A systematic review of SM interventions for adolescents living with HIV (ALWHIV) found that, although the evidence is very uncertain, these interventions have the potential to increase adherence and decrease viral load (Crowley & Rohwer, 2021:25).

The ALWHIV and YLWHIV need skills to self-manage an array of challenges that include adhering to treatment (the medical management of their illness) as well as coping with HIV and stigma to develop key SM abilities such as problem-solving, goal setting and self-evaluation (Crowley et al., 2020:2).

With increasing access to ART in low-resource settings, greater numbers of children are surviving into adolescence and adulthood. Therefore, there is need to support them to live positively with the condition (Nöstlinger, 2015:9).

The transition from being a dependent child to becoming an independent youth forms part of living positively with HIV. This transition process can be demonstrated by youth taking a greater responsibility for tasks such as taking medication as scheduled, attending appointments, filling prescriptions, filling out medical paperwork, and making appointments independently. It is crucial to note that, while each youth is different, the ability for youth to take on these tasks will likely require a period of several years. Transition should build upon the strengths of the individual client's home and community support systems (Iribarren, Siegel, Hirshfield, Olender, Voss, Krongold, Castillo & Schnall, 2019:7). Therefore, developing autonomy and SM abilities is a continuous process that may impact future health outcomes and, hence, cannot be overemphasised in YLWHIV (Cutler et al., 2018:359). In addition, supporting youth living with chronic conditions to build self-confidence, develop a positive body image, self-appreciation, maintaining positive thinking, stress management, and acceptance of the condition is important to promote SM (Sattoe et al., 2015:705).

2.7 Factors influencing self-management

Here the factors influencing SM, as depicted in the conceptual framework presented in chapter 1, will be discussed. These factors are condition-specific, physical and social characteristics, and the individual and family characteristics.

2.7.1 Condition-specific factors

Condition-specific factors influencing SM include type of medication/regimen, frequency of medication, being ill or stable, and the illness trajectory.

2.7.1.1. Type of medication/regimen

Complexity of the treatment regimen is one factor that has been identified to affect SM. Complex treatment regimens may negatively influence the patient's ability and motivation to self-manage, as well as the quality of SM experiences. The quality of SM depends on how challenging or smoothly SM proceeds Schulman-Green, Jaser, Martin, Alonzo, Grey, McCorkle, Redeker, Reynolds & Whittemore (2012:140).For instance, youth with complex regimens such as a second line regimen with twice daily drug doses, may find it difficult to self-manage their treatment. This will affect the youth's motivation to comply with such, due to the high pill burden and more possible side effects. Medication side effects discourage youth from taking their medication, which will have a negative impact on SM (Schulman-Green, Jaser, Martin, Alonzo, Grey, McCorkle, Redeker, Reynolds & Whittemore, 2012:140; Millard, Elliott & Girdler, 2013:103).

There are different preferred first line regimens for YLWHIV. The available ART options help to promote the quality of life in YLWHIV. Combination treatment taken once daily is mostly preferred.The recommended regimen for adolescents and adults which is in lign with the WHO guidelines includes Tenovovir (TDF), Lamivudine (3TC) and Dolutegravir (DTG) (Government of Lesotho, 2016:2).

2.7.1.2 Frequency of medication

Schulman-Green et al. (2012:140) point out that other significant factors influencing SM include pill burdens and the frequency that the medication is taken. If YLWHIV has more medications to take at the same time, it becomes a burden and the youth become demoralised by the many pills they need to take (Sharer & Fullem, 2012:11).

2.7.1.3 Being ill or stable

Persons living with HIV come across challenges related to a host of symptoms and side effects regarding the disease, its treatments, and comorbidities. The severity of one's HIV related symptoms decreases one's health and wellbeing. If YLWHIV is not healthy, they will not be motivated to attend clinic appointments, they will not engage in behaviours that promote health, such as exercise and taking medications as prescribed (Reynolds, Sanzero, Eller, Nicholas, Corless, Kirksey, Hamilton et al., 2011:2). A study conducted in Cape Town, South Africa by Crowley (2018:46), highlighted that if there were more reported illness symptoms, those were associated with lower SM.

Successful management of HIV symptoms is therefore key in achieving good health outcomes. YLWHIV therefore need to be empowered and invigorated to ensure self-care activities such as healthy eating, getting adequate rest, and attending healthcare services, which will in turn influence SM (Lozano & Houtrow, 2018: s235).

2.7.1.4 Illness trajectory

Illness trajectory refers to the events that occur during an illness and is influenced by the individual's reaction to the illness, experiences with others, and interventions (Reed & Corner, 2015:10). The HIV trajectory is described as the transition from wellness to the illness. Initially, YLWHIV may present with a primary infection. This is followed by a clinical latent period, development of opportunistic infections, and finally an AIDS defining illness if no treatment is initiated. The survival patterns of YLWHIV can be categorised into the "typical progressors", "rapid progressors", "long-term non-progressors" and "long-term survivors". The majority of persons living with HIV have exhibited a typical pattern of progression in which primary infection is followed by a period of clinical latency of up to 6-8 years (Brashers, Neidig, Reynolds & Haas 2017:67).

However, with access to ART, disease progression can be slowed down (Brashers et al., 2017:67). In lign with the WHO guidelines,all persons diagnosed with HIV should be initiated on ART (test and treat) regardless of their clinical, immunological and virological status (Government of Lesotho, 2016:2). In comparing the trajectories of the perinatally and behaviourally infected youth, Lowenthal et al. (2014:4) emphasise that perinatally infected YLWHIV may be affected by comorbid illnesses such as cancer, chronic diseases, and mental health issues. All these may alter their illness trajectory and have a negative impact on normal growth, including psychological wellbeing and socialisation.

Behaviourally infected youth acquire HIV through risky behaviours and are usually older (usually above 15), are often healthy, and they are likely to be in sexual relationships. These youth are usually healthier as their growth and development occurred normally (WHO, 2010:63). The YLWHIV's course of illness and the events surrounding such course of illness have a strong influence on SM. Both the perinatally and behaviourally infected youth, at a certain age must transition from paediatric to adult care. This may influence their trajectory as they tend to disengage with care during the transition. For both groups, acquiring another illness such as tuberculosis may also change their trajectory (WHO, 2010:65).

2.7.2 Physical and social environment

The social environment that influences SM include schools, peers, and the neighbourhood (Modi, Pai, Hommel, Hood et al., 2012:31). Individuals and families manage chronic conditions in the context of such broader communities. These communities need to provide a supportive and enabling environment to encourage YLWHIV to maximise their potential despite the chronic condition. Under this section, access to healthcare facilities and adolescent-friendly health services will be discussed as components of the physical and social environment.

2.7.2.1 Access to healthcare facilities

Access to health services means that the services are geographically, functionally financially, and culturally acceptable and accessible to the youth (Hattingh, Dreyer & Roos, 2008:30). Antiretroviral therapy services for YLWHIV must be within the primary healthcare setting as primary healthcare is an essential part of the comprehensive health service. An ideal primary healthcare setting should meet all the daily health needs of the youth. When these services are accessible in a manner that motivates youth to attend, it will minimise missed clinic appointments and non-adherence, hence SM will be improved (Vasuthevan & Mthembu, 2014:40).

Geographic disparities contribute to environmental barriers that may affect SM behaviours in people who have chronic illnesses. This implies that, the harder it is to get to the clinic and the further apart the clinic is from the youth, the interest to utilise such services will deteriorate. Lack of access to transport leads to missed appointments to health facilities (Grady & Gough, 2014:e28). Moreover, when an adolescent has enough money and safe access to the clinic, whether on foot or through public transport, they can remain in care and adhere to ART treatment (Cluver et al., 2018:9).

Cluver et al. (2018:1), in a study conducted in South Africa, discovered that increased retention in care of YLWHIV are associated with youth-friendly health facilities with flexible working hours such as hours as well as having providers that are trained in adolescent care. Adolescents do not prefer to stay for long hours at the clinics and they dislike queuing with all the other patients. Hence, they may need to attend after hours at their own convenience. The introduction of decentralisation of healthcare services through mobile clinics and school health programmes that provide screening services, medication collection and basic treatment with onward referrals may increase access and free facilities (Pike, Celum & Gail-Bekker, 2020:1). Another best practice necessary to improve youth's access to healthcare are healthcare providers who schedule time for off-site centres that provide quick, easy access, which may be desirable to adolescents (Pike et al., 2020:1).

2.7.2.2 Adolescent-friendly health services

Youth-friendly services are within reach of adolescents. These are the services that meet adolescents' needs. They are in the right place, at a cost that youth can afford or even free of charge where necessary. They are delivered in the right manner to be acceptable to youth. These services are effective, safe and affordable. Youth return to these services when they need to and they even recommend the services to friends (Government of Lesotho, 2017:11). In addition, services such as free HIV testing and free condoms must be available at all times (Gage, Do & Grant 2017:8). There are various barriers to HIV treatment for adolescents and they experience difficulty in transitioning from paediatric to adult healthcare. As a result, there have been more calls for initiatives to develop adolescent-responsive health systems. Adolescent-friendly clinics and peer support programmes are examples of such, particularly in Sub-Saharan Africa (Cluver et al. 2018:4).

Adolescent- and youth-friendly services constitute best practices that will improve the health of youth and adolescents. These kinds of services improve SM because youth become more motivated and inspired to utilise the health services. The implementation of such projects should involve youth and adolescents in the design and implementation of services targeted at improving their health (Gage et al., 2017:8).

Pike et al. (2020:1) also affirm that, in terms of waiting periods, long waiting times at healthcare facilities, influenced by patient–nurse ratios, type of service and time of arrival, are hindrances to YLWHIV accessing healthcare services. They further indicate that clear healthcare information strategies, including appropriate infographics inside and outside the clinics could make appointments and clinic attendance more efficient.

2.7.3 Individual and family characteristics

Individual and family SM includes incorporating health-related behaviours into a person's or family's day-to-day activities. Individual or family SM prevents or attenuates illness or facilitates the management of complex health regimens in ways that reflects individual or family values in personally meaningful ways (Sawin, 2017:173). In this section, the age of the adolescent, psychological strengths and difficulties, and health literacy are discussed.

2.7.3.1 Age

Growth and development are continuous processes that occurs throughout one's life span. Youth's brain maturation continues to occur through the entire span of their youth. After puberty, the youth's brain may have matured to some extent; however, he/she may still not be able to relate the future to the occurrences taking place now (WHO, 2010:14). One of the characteristics of adolescence is their eagerness to attain some self-control and independence from parents. As youth continue to grow, they may exhibit improvements in problem solving abilities. Hence, youth in early adolescence may have challenges with SM as opposed to late adolescence (Chao, Whittemore, Minges, Murphy & Grey, 2014:2).

Later in adolescence, youth exhibit some reasoning and logical thinking ability. They are more able to express their feelings, speak their mind and make complex decisions (Newman & Newman, 2012:359). Older adolescents may encounter life experiences that may bring about stress and feelings of mental and emotional instability. These feelings of emotional instability may be exacerbated by the discovery of their HIV status, by experiences such as the death of a family member, or if the youth is stigmatised and rejected by their peers. Therefore, SM is compromised if the youth experience stress and emotional instability, as they tend to neglect their health (Lowenthal et al., 2014:9).

2.7.3.2 Psychological strengths and difficulties

The strengths and difficulties (psychological attributes) that adolescents and youth experience will also affect their ability to self-manage. Psychological strengths are prosocial behaviours and psychosocial difficulties include conduct problems, hyperactivity-inattention, emotional symptoms, and peer problems (Hoonsen, Lee Davids et al., 2018:35). A study conducted in Cape Town, South Africa discovered that psychological strengths are associated with better SM amongst ALWHIV (Crowley, 2018: 239).

Initial symptoms of mental health difficulties begin during adolescence. Youth living with HIV may encounter mental health challenges. Most YLWHIV encounter stress, due to loss of parents, and body image related challenges. If youth have to ensure the settlement of bills, such as the payment of their own school fees due to lack of parent or caregiver support, it may also lead to stress. Youth living with HIV may also encounter stress due to stigma and this may predispose them to being vulnerable to drug and substance abuse (Dow, Turner, Shayo, Mmbaga, Cunningham & O'Donell, 2017:2).

Elevated anxiety levels are among the psychological problems that YLWHIV face and may lead to non-adherence and drug misuse. Psychological problems/vulnerabilities may lead to poor adherence and eventually high viral loads (Chenneville, Gabbidon, Lynn & Rodriquez, 2018:9). Higher levels of resilience were significantly associated with decreased behavioural issues among potentially susceptible HIV-affected adolescents, according to the findings of a study done among adolescents in South Africa (Kuo, LoVette, Pellowski, Harrison, Matthews, Operio, Beardslee, Stein & Brown, 2019:S33).

2.7.3.3. Health literacy

Knowledge of the treatment and health literacy of a YLWHIV constitutes mental processes affecting SM (Modi et al., 2012:49). The present study is going to focus and investigate whether YLWHIV are aware of their CD4 count, their viral load, their next clinic appointments, and their knowledge about why they are taking their treatment. The longer a young person has lived with a chronic disease, the more they learn about the symptoms and how to manage them. This gives them the experience of how to properly manage themselves while sick. SM is different for youth who were diagnosed early in life because they may have acquired habits where their parents and caregivers have a greater influence in HIV SM. The parents may have primarily reinforced SM education (Chao et al., 2014:2).

In addition, Navarra, Neu, Toussi, Nelson and Larson (2014:8) discovered that positive outcome expectancy beliefs and functional literacy skills were found to predict self-reported adherence. If a youth can read, write, and comprehend some concepts, he or she is more likely to comply with treatment, follow directions, and accept SM advice. In a study conducted in Cambodia, poor treatment literacy and a lack of understanding of the importance of ART as a preventative rather than a curative intervention, affected adherence negatively (Chhim, Mburu, Tuot, Sopha, Khol, Chhoun & Yi, 2018:8).

2.7.3.4. Family structure and functioning

Modi et al. (2012:60-62) state that family structure and functioning, as well as how well the family is involved in the young person’s health condition, will affect SM. Illness and the loss of a parent places the youth in a difficult situation, which affects their SM abilities. These youth may be left with the responsibility of taking care of younger siblings or other ill family members. The HIV orphaned youth experience various unpleasant consequences. These include a lack of guidance, and supervision, inconsistent care, psychological distress and poor mental health, loss of education opportunities, and greater vulnerability to sexually transmitted infections (Lowenthal et al., 2014:10).

Being orphaned, the lack of a stable home environment or abusive home environments, non-disclosure by parents or caregivers, as well as the lack of support from family, caregivers and treatment supporters all have a negative impact on SM (Egpaf, 2014:8). Moreover, YLWHIV face denial, secrecy, child-parent disputes, stigma, and prejudice, which may trigger self-hatred, anxiety, and a lack of confidence

(Kaunda-Khangmwa, Kapwata, Malisita, Munthali, Chipeta, Phiri & Maderson, 2020:10).

In contrast, facilitators of SM have been discovered to be stigma-free home environments; safe, inclusive households; disclosure of HIV status by caregivers and parents; and support from family and caregivers. All these factors will lead to a smooth transition process, where SM abilities will be improved and maintained (Egpaf, 2014:10). Cluver et al. (2018:5) also affirm that retention in care of youth and adolescents is increased when family support is good. The results of the study done in South Africa indicate that being accompanied to the clinic was associated with doubling the odds of retention, which lead to improved SM and improved quality of life in YLWHIV.

Beachan and Deatrick (2014: 5) emphasise that, since developing autonomy and SM abilities in YLWHIV is a continuous process that affects future health outcomes, parents should be involved as team players in promoting SM. When the parents of YLWHIV are provided with ongoing support, they are also able to support their children to live better with HIV and, as a result, health outcomes are improved (Beachan & Deatrick 2014:5).

2.8 Conclusion

It remains of utmost importance to explore and investigate factors influencing SM in YLWHIV for various reasons. Studies indicate that YLWHIV experience challenges with taking care of themselves and living well with HIV due to different factors. Knowledge of these factors will contribute to the increased quality of life among youth. Currently, HIV still accounts for a high mortality rate amongst YLWHIV in Africa and new infections amongst the youth is not showing a satisfactory decline. The results of this study may contribute to identifying factors influencing SM of YLWHIV in the context of Lesotho to develop tailored SM support strategies. The discussion of the research methodology will follow in the next chapter.

CHAPTER 3

RESEARCH METHODOLOGY

3.1 Introduction

In the previous chapter, the literature related to the factors that influence the self-management (SM) of youth living with HIV (YLWHIV) was reviewed. Chapter three includes an in-depth discussion of the research design and the methodology that was employed. A quantitative design was used to investigate the factors that influence the SM in YLWHIV. An overview of the research methodology was provided in chapter 1 and, in this chapter, a detailed description is provided.

3.2 Aim and objectives

The study aimed to describe the factors that influence the SM of YLWHIV in Lesotho. The specific objectives were to:

- Establish the condition-specific factors influencing SM of YLWHIV in Lesotho.
- Ascertain the physical and social environmental factors influencing SM of YLWHIV in Lesotho.
- Determine the individual and family characteristics influencing SM of YLWHIV in Lesotho.

3.3 Study setting

The study was conducted at Scott Hospital and Matelile Health Centre. Scott Hospital is in Morija in the southern part of Lesotho, about 45 kilometres from the capital city, Maseru. Scott Hospital is a private institution governed by the Lesotho Evangelical Church in Southern Africa (LECSA) but receives subvention from the Government of Lesotho. Services offered by the hospital include in-patient and out-patient services. Scott Hospital provides supervisory support for 19 health centres; Matelile Health Centre is one of them. Matelile is located towards the south of Scott Hospital and it is about 15 kilometres from Morija. Matelile Health Centre only provides out-patient services from Monday to Friday. It is surrounded by many villages, which makes it accessible; most youth access services there, including antiretroviral therapy (ART).

Youth corners are special health facilities available within the hospitals where youth access all health services, including ART, separately from where adults receive services (Elizabeth Glaser Paediatric Foundation, 2014:3). However, at the clinics (health centres), youth access ART from the ART corners where adults also access it. At the adolescent-friendly health facilities, services are tailor-made to meet the needs of youth. There are initiatives such as peer clubs where youth attend only with their peers; they can share ideas and experiences. In addition, at the adolescent health corners, youth can be consulted by trained health personnel who are able to listen to their concerns, provide advice, and address challenges that these youth experience. Caregivers who can attend are also invited if a youth is under 18 years (Gage et al., 2017:2).

Scott Hospital is within the area where the researcher is based, working as a Nurse Educator at the Scott College of Nursing. The college and the hospital are under the proprietorship of LECSA. Although youth can still access ART from other health centres, Matelile Health Centre was chosen for this study because it is the facility where most of the YLWHIV receive services. In Lesotho, ART is accessed free of charge. According to the 2016 ART guidelines, as soon as a youth is tested HIV positive, they are initiated on ART irrespective of the CD4 count, viral load or WHO clinical staging (Government of Lesotho, 2016:39). Adolescents over the age of 15 and youth are given the same regimen as adults (Government of Lesotho 2016:16). Figure 3.1 shows the study settings.

Figure 3.1: Study settings (Google Maps 2020)

3.4 Research design

According to Gray, Grove and Sutherland (2017:676), a research design is described as the researcher's plan to answer the research questions, including considering the number of people to participate in the study and how the data will be collected. The researcher utilised and exploratory-descriptive, cross-sectional quantitative research design, as discussed below.

3.4.1 Quantitative design

According to Brink, Van der Walt and Van Rensburg (2018:11), quantitative designs focus on a relatively small number of concepts. In addition, structured processes and formal instruments are used to collect data; questionnaires are examples of formal instruments that can be used in quantitative designs. Data in this design is collected in a controlled manner and statistical procedures are used to analyse data (Brink et al., 2012:11). This design was chosen because the researcher wanted to obtain data objectively utilising structured procedures

3.4.2 Cross-sectional design

Brink et al. (2012:210) describe cross-sectional studies as those that collect data from study participants at one point in time. Cross-sectional studies can be exploratory and descriptive (Brink et al., 2012:101). The exploratory and descriptive aspects of this design are discussed in the following sections.

3.4.3 Exploratory research

Polit and Beck (2017:728) define exploratory research as a study that explores in-depth dimensions of a phenomenon. Exploratory research assists in providing insight into the various ways in which phenomena manifest. In the context of this study, the researcher explored the factors that influence the SM of YLWHIV in Lesotho.

3.4.4 Descriptive design

According to Polit and Beck (2017:206), descriptive designs are used to observe, describe and document a phenomenon in its natural environment. Descriptive designs can also be used for hypothesis generation or when developing a theory. After exploring the factors that influence the SM of YLWHIV, the researcher described the factors. In addition, the researcher explored if the contextual factors, as described in the Individual and Family Self-Management Theory (IFSMT) were relevant in the context of Lesotho. Although the research also contained an analytical component where regression analysis was performed to determine the influence of the dependent contextual variables on SM, the primary aim was to describe the various contextual factors influencing SM in the context of Lesotho and the statistics employed in the data analysis were predominantly descriptive (Gray et al., 2017:208).

3.4.5 Research paradigm

According to Brink et al. (2012:24), a research paradigm refers to a set of assumptions about basic kinds of entities in the world and how these entities interact. The researcher followed a post-positivist paradigm.

3.5 Population and sampling

3.5.1 Population

The population of a study refers to the entire aggregation of cases in which a researcher is interested (Polit & Beck, 2017:249). The target population comprised youth who are HIV positive and on ART. The total number of YLWHIV who are accessing ART services at Scott Hospital and Matelile Health Centre is 368.

3.5.2 Sampling technique

Sampling refers to the process of selecting cases to represent an entire population (Polit & Beck, 2017:251). There are two types of sampling techniques: probability and non-probability. Probability sampling is the method where all elements in the population have an equal chance of being included in the sample. Non-probability sampling is the method in which a sample is selected from elements through non-random methods. In this method the researchers prefer the participants who have knowledge about the phenomenon (Brink et al., 2012:134). In this study, the researcher employed non-probability sampling. Convenience sampling was used to select participants. Polit and Beck (2017:276) define convenience sampling as the technique in which the researcher uses readily available participants for the study. The sampling method was chosen due to the different appointment schedules of adolescents. Only a certain number of youths attend scheduled appointments at a time. It was, therefore, more practical for the researcher to approach readily available adolescents when they attended their follow-up appointments. This sampling method also ensured that the participants did not incur additional travelling costs for participating in the study. The limitation of this sampling method is that only youth attending clinic appointments were included in the study.

3.5.3 Sample size

The researcher recruited 184 participants; 94 of them were recruited at Scott Hospital, while 90 of them were recruited from Matelile Health Centre from where most youth access ART. A larger number was recruited from Scott Hospital because it serves a larger population than the clinics. The sample size was calculated with the help of a statistician from Stellenbosch University. One-hundred-and-eighty-four (184) participants are required to test the null hypothesis that none of the 12 predictors were associated with the outcome, which is SM, versus an alternative hypothesis that at least one of the predictors has a moderate associational effect on SM. The 12 predictors included the following: individual (age, strengths and difficulties, health literacy, family structure and functioning); those pertaining to the physical and social environment (healthcare access and transport, adolescent-friendly services); and the condition-specific factors (type of medication, trajectory and condition stability).

3.5.4 Inclusion criteria

According to Brink et al. (2012:56), sampling criteria ensure that the researcher has selected participants that are appropriate for the study. Those who do not meet the criteria are excluded while those who meet the criteria are included. The following were the inclusion criteria for study participants:

- Youth who are living with HIV
- Between the ages of 15 and 24
- Accessing ART care at Scott Hospital and Matelile Health Centre
- Perinatally or behaviourally infected
- Aware of their HIV status, which was determined by asking them and confirming with information from their patient files.

3.5.5 Exclusion criteria

The following was the exclusion criteria for study participants:

- HIV-positive youth who are lost to follow-up and were not accessing care at the time of the study.

3.5.6 Recruitment process

Potential participants who met the inclusion criteria were recruited. While potential participants were in the waiting area for ART services, individual potential participants were approached by the fieldworker. The researcher and the fieldworker accessed participants with the assistance of healthcare workers in the adolescent health corners. Healthcare workers in the adolescent health corners assisted the researcher and fieldworker to identify adolescents who are living with HIV, were aware of their HIV status, and were due for follow-ups/check-ups.

The fieldworker was a newly qualified professional nurse who was till unemployed. The fieldworker was co-opted to assist in data collection to ensure that all participants attending the study sites could be invited to participate. Before commencement of data collection, the fieldworker was given training about the data collection process, the questionnaire, issues of informed consent, and ethical considerations. The fieldworker explained the purpose of the study, confidentiality and informed consent to the potential participants. They were also made aware that data will be collected by means of a self-administered questionnaire of which the completion time was about 30 minutes. One-hundred-and-eighty-four (184) participants were approached. Those who agreed to participate were given consent forms to sign and, after they had signed the consent forms, they were given the questionnaire to complete.

All 184 participants agreed to participate. However, one participant started the questionnaire but withdrew in the middle of the data collection process. The questionnaire was then discarded. As advised by the Health Research Ethics Committee (HREC), participants younger than 18 years were given information forms to take home to their parents to inform them of the study and provide the contact details of the researcher should they have questions.

HREC waived parental consent for youth 15 to 18 years whose parents could not come to the hospital because parents do not always accompany adolescents due to long waiting periods. It is also difficult to obtain telephonic consent because some families do not have phones. In some parts of the country, people do not have access to electricity, so even if they have phones, charging them remains a challenge.

3.6 Data collection tool

A questionnaire is a written self-report form intended to elicit information from a participant’s written responses (Gray et al., 2017:689). A questionnaire was used because it was a rapid way of obtaining data from a large group of people. In addition, participants may feel a greater sense of privacy and are more likely to offer honest answers (Brink et al., 2012:153). The researcher used a validated tool. The components of the questionnaire addressed the three domains of the factors that influence SM, namely individual and family, physical and environmental, and condition specific.

The questionnaire consisted out of five sections:

Section 1: Background information: This include]ed 26 questions about the young person, their family, and their health. These questions pertain to the individual (age, gender) and family factors (family structure and functioning). This section also contained questions about the young person's health, including their mental health. Health literacy was measured by asking whether they know how they acquired HIV and what they understood about their CD4 count and viral load. The responses were mostly measured on a nominal level.

Section 2: Their treatment: This section included nine questions about the antiretroviral treatment the adolescent (nominal level measurement) is taking and their adherence to treatment (ordinal level measurement). These questions pertain to the condition-specific factors.

Section 3: Their hospital or clinic: This section included six questions about the adolescents' satisfaction with healthcare services, adolescent-friendly services and transportation. These questions relate to the physical and environmental factors and was measured on a nominal level (yes / no) and a scale that used "always, usually, sometimes and never''

Section 4: Self-management: This section included 44 items that measured SM. The Adolescent HIV Self-Management Scale (AdHIVSM) has been developed in South Africa and has high validity and reliability (Crowley, 2018). The questions were measured on a Likert-type scale from 'strongly disagree / never = 1' to 'strongly agree / always = 4'. Some items were negatively phrased and inversely coded.

Section 5: Strengths and difficulties: This section contained 25 questions measuring the strengths and difficulties using a standardised questionnaire. The Strengths and Difficulties Questionnaire (SDQ) provides information about individual factors (Hoonsen et al., 2018:33; Goodman, Lamping & Ploubidis, 2010:1183). The measurement scale includes options for 'not true = 0', 'somewhat true = 1' and 'certainly true = 2'. Some items were inversely phrased and coded according to the guidelines provided by the SDQ (Hoonsen et al., 2018:4).

The researcher and the fieldworker obtained the most recent routinely performed viral loads tests from the folders. The questionnaire was translated into Sesotho. The translation process included a forward translation of the questionnaire, and then one person with expertise in translation was requested to double check the translation and compare it with the English version of the questionnaire. If there were discrepancies, the two people resolved them before the questionnaire was used (see Appendix 6). All the questions in the questionnaire have been previously used in a study in Cape Town and were found to be reliable and valid (Crowley, 2018:200).

3.7 Pilot study

A pilot study is a small version of the intended study performed prior to the main study on a few participants from the entire population (Brink et al., 2012:174). This study was piloted on 10% of youth from the sample. Pilot data collection dates were from the 18th of September 2020 to the 1st of October 2020 at Scott Hospital and on the 6th of October 2020 at Matelile Health Centre. The actual number of youths for the pilot study was 18 YLWHIV on ART. The pilot study was conducted to determine the feasibility of the main study. In addition, the pilot study was conducted to check that the English and Sesotho translated versions of the questionnaire were understood by the participants. Thirteen questionnaires were in Sesotho, while five were in English.

The researcher recruited the first 10 readily available participants from Scott Hospital and 8 from Matelile Health Centre. The data from the pilot study was not included in the main study. Item 18 on the data collection tool, which assessed the youths' understanding of their CD4 count, and item 20, which enquired about their understanding of their viral load, were removed from the data collection tool as none of the participants could respond to the questions. It was, therefore, decided to only keep the questions related to their knowledge of the CD4 count and viral load values as a measure of health literacy.

3.8 Validity and reliability

According to Gray et al. (2017:375), validity is defined as a quality criterion referring to the degree to which inferences made in a study are accurate and well-founded. It indicates the extent to which the instrument measures what it is intended to measure.

Content validity and reliability of the AdHIVSM and SDQ instruments have been assessed in previous studies (Crowley, 2018; Goodman et al., 2010). The researcher further established the content validity of the AdHIVSM instrument by doing factor analysis on the new sample (see Table 3.2).

Reliability of an instrument denotes the steadiness of the measures obtained from a characteristic, notion or a condition in a study or clinical practice (Gray et al., 2017: 370). Reliability is further defined as the degree to which scores for people have not changed, are similar across recurring dimensions under several situations, including recurrence on altered incidences or in different editions of a measure (Polit & Beck, 2017:303). Reliability was tested using Cronbach's alpha. As mentioned in the previous section, the reliability of the AdHIVSM and SDQ has been assessed in previous studies. Cronbach's alpha of the SDQ questionnaire previously yielded reliability coefficients of 0.65-0.85 (Hoonsen et al., 2018:33; Goodman et al., 2010:1183), indicating acceptable internal reliability. For AdHIVSM, Cronbach's alpha was 0.84 in the South African study where it was developed amongst adolescents aged 13-17 (Crowley, 2018).

However, in the present study the reliability values of the AdHIVSM total scale and subscales were not acceptable, except for the HIV biomedical management subscale (see Table 3.1). Similarly, the SDQ subscale had low Cronbach alpha values.

Table 3.1: Reliability values of the AdHIVSM and SDQ in the current sample

Scale / subscale	Alpha	N
AdHIVSM		
Total scale (35 items)	0.508	183
Believing and knowing subscale (8 items)	0.631	183
Goals and facilitation (8 items)	0.067	183
Participation (10 items)	0.066	183
HIV biomedical management (4 items)	0.893	183
Coping and self-regulation (5 items)	0.031	183
SDQ		
Total difficulties (20 items)	0.604	182
Emotional problems scale (5 items)	0.487	183
Conduct problems scale (5 items)	0.523	183
Hyperactivity scale (5 items)	0.229	182
Peer problems scale (5 items)	0.387	183
Prosocial scale (5 items)	-0.055	183

Since the AdHIVSM was found to not be reliable in the study context, except for the HIV biomedical management scale, an item analysis was performed on the scale until items lowering the reliability of the scale was removed. This process led to the retention of 25 items.

After this, an exploratory factor analysis was performed on the 20 items to confirm the structural validity of the remaining items. The Kaiser-Meyer-Olkin measure of sampling adequacy was adequate for factor analysis (0.804) and the Bartlett's Test of Sphericity was statistically significant ($p<0.001$). The Screen Plot suggested retaining three factors. Three components were extracted and explained 48.9% of the total variance in the scale (Table 3.2). Factors had loadings of 0.2 and above on these components. These components resembled the medical, emotional and social/role management components of SM as originally described by Lorig and Holman (2003:1).

Table 3.2: Exploratory Factor Analysis (EFA) item factor loadings

Component Matrix[a]			
	Component		
	1	2	3
5_Self-management: I can achieve as much as other people who don't have HIV	.162	-.216	.536
7_Self-management: I am confident that I can take care of my health	.073	-.292	.608
8_Self-management: I would cope if I told someone about my HIV status and that person didn't accept it or ignored me	.259	-.415	.403
10_Self-management: I decide by myself whom I want to tell about my HIV status	.182	-.417	.492
11_Self-management: I can cope with it if people say nasty or hurtful things about people living with HIV	-.018	.690	.436
12_Self-management: Doing things I like (for example listening to music, reading or playing sport) helps me to cope	.151	.682	.339
14_Self-management: I aim to be independent (taking care of myself)	.126	.424	.320
15_Self-management: I aim to enjoy life, feel good and have fun	.320	.418	-.093
18_Self-management: I do things to improve my health (for example, by exercising or eating healthy foods)	.199	.217	.104
20_Self-management: I attend clinic appointments on scheduled dates (for example, I use a calendar, phone or my clinic card to remind myself)	.491	-.024	-.151
22_Self-management: I ask the doctor or nurse questions when there is anything I don't understand	.348	.242	-.092
29_Self-management: I have regular contact with friends (for example, at school or in my community)	.327	.313	.284
32_Self-management: I understand why I am taking ARVs	.912	-.004	-.043
33_Self-management: I know the names of my ARVs	.802	-.169	-.117
34_Self-management: I know at what times I should take my ARVs	.755	.071	-.007
35_Self-management: I know what to do when I miss the time to take my ARVs	.936	-.002	-.090
36_Self-management: I understand what will happen if I don't take my ARVs every day	.943	.006	-.096
37_Self-management: I know what my viral load is	.822	-.137	-.051
38_Self-management: I know what my viral load should be	.810	-.051	-.055
41_Self-management: I plan how to take my ARVs when I am not at home (for example, when I am out with friends or go on a school camp)	.056	-.353	.243
Extraction method: Principal component analysis			
a. 3 components extracted			

Self-efficacy (role/identity management) = items 5, 7, 8, 10, 41

Resiliency/ positive attitude (emotional management) = items 11, 12, 14, 15, 18, 29

Medical management = items 20,22,32,33,34,35,36,37,38

Reliability analysis was performed on the 20 items that yielded a Cronbach alpha of 0.804. These items were, therefore, used to calculate an SM score for the YLWHIV in this study (Table 3.3).

Table 3.3: Item-total statistics of retained items

	Scale mean if item deleted	Scale variance if item deleted	Corrected item-total correlation	Cronbach's alpha if item deleted
7_Self-management: I am confident that I can take care of my health	70.22	17.787	.075	.806
5_Self-management: I can achieve as much as other people who don't have HIV	70.28	17.488	.147	.805
8_Self-management: I would cope if I told someone about my HIV status and that person didn't accept it or ignored me	70.21	17.638	.160	.804
10_Self-management: I decide by myself whom I want to tell about my HIV status	70.28	17.358	.146	.806
11_Self-management: I can cope with it if people say nasty or hurtful things about people living with HIV	70.62	17.126	.141	.809
12_Self-management: Doing things I like (for example listening to music, reading or playing sport) helps me to cope	70.66	16.478	.254	.804
14_Self-management: I aim to be independent (taking care of myself)	70.78	16.721	.189	.809
15_Self-management: I aim to enjoy life, feel good and have fun	70.44	16.655	.305	.799
18_Self-management: I do things to improve my health (for example, by exercising or eating healthy foods)	70.63	16.850	.196	.806
20_Self-management: I attend clinic appointments on scheduled dates (for example, I use a calendar, phone or my clinic card to remind myself)	70.37	16.585	.379	.795
22_Self-management: I ask the doctor or nurse questions when there is anything I don't understand	70.75	16.088	.297	.802
29_Self-management: I have regular contact with friends (for example, at school or in my community)	71.26	15.489	.340	.802
32_Self-management: I understand why I am taking ARVs	70.32	15.692	.759	.778
33_Self-management: I know the names of my ARVs	70.47	14.921	.598	.779
34_Self-management: I know at what times I should take my ARVs	70.37	15.398	.615	.780
35_Self-management: I know what to do when I miss the time to take my ARVs	70.33	15.575	.778	.777
36_Self-management: I understand what will happen if I don't take my ARVs every day	70.34	15.522	.786	.776
37_Self-management: I know what my viral load is	70.40	15.198	.654	.777
38_Self-management: I know what my viral load should be	70.40	15.011	.671	.775
40_Self-management: I plan how to take my ARVs when I am not at home (for example, when I am out with friends or go on a school camp)	70.18	17.918	.056	.806

Since the SDQ has been used in several parts of the world, the subscales were retained, but the results will be interpreted with caution (especially the prosocial subscale). It is noted in the literature that authors commented on difficulties in the translation and back-translation of the SDQ in African languages (Hoonsen et al., 2018:2).

3.9 Data collection

After approval to conduct the study by the HREC of Stellenbosch University (Approval number S20/06/139) and the Ministry of Health Lesotho (Ref. ID 104-2020), the researcher wrote a request letter to the medical superintendent of Scott Hospital, who is also responsible for Matelile Health Centre, for permission to conduct the study.

The researcher and fieldworker distributed questionnaires to readily available potential respondents who voluntarily agreed to participate in the study by signing the informed consent forms as proof of voluntary participation. The researcher administered questionnaires at Scott Hospital during the scheduled appointments. Covid-19 affected the appointment such that only a limited number of youths were scheduled at the time. During data collection, Covid -19 protocols were always adhered to. The field worker and the participants were wearing masks all the time, in the interview room it was only one participant and the field worker at a time. The dates of data collection were from 16 November 2020 to 27 November 2020. At Matelile Health Centre, a trained fieldworker administered questionnaires to youth who attended appointments. Data collection at Matelile Health Centre was from 30 November 2020 to 18 February 2021.

The researcher or fieldworker was always available for the youth to answer questions. The actual time that was taken to complete the questionnaire was 40 minutes.

Privacy was ensured throughout the data collection process at both sites. A room, which was not in use, was requested so that the participants could freely complete the questionnaire in a private space and without disturbance.

3.10 Ethical considerations

Ethical principles were followed throughout the data collection process. These principles include informed consent, beneficence, the right to self-determination, and the right to privacy

3.10.1 Informed consent

Informed consent in this study refers to participants' consent to participate in the study. An informed consent form (Appendix 3) was issued to participants who had the mental ability to consent to participate in the study and were above 15 years. The researcher asked HREC to waive parental consent for participants who were younger than 18 years (15-17) and permission was granted. The researcher ensured that all participants were provided with an informed consent form in the language of their choice, which was either Sesotho or English. When the youth showed understanding of the information in the consent form, could retain the information, and used the information as part of the decision-making process, the researcher concluded that the participant had the mental capability to participate in the study. The researcher or fieldworker was always present to explain anything to the participants that they did not understand in the language of their choice. For participants who were under the age of 18 years, an information leaflet was sent home with them to provide information about the study.

3.10.2 Beneficence

This principle obliges the researcher to lessen harm and capitalise on benefits (Polit & Beck, 2017:139). At the time when the participants were filling in the questionnaire, they were monitored in case they became distressed. Counselling services were available and participants would have been referred to the on-site counsellor who is familiar to the youth. However, none of the participants showed any signs of distress. The researcher and fieldworker ensured that each participant’s HIV status were not disclosed inappropriately. This was ensured by the researcher who checked with the healthcare workers whether the adolescent was aware of their status or not.

In this study the participants did not incur any costs, as they were recruited when attending already scheduled appointments. The researcher, however, compensated the participants for time spent filling in the questionnaire by providing them with refreshments costing approximately R20.00 each.

3.10.3 The right to self-determination

This principle determines that participants can voluntarily decide whether to take part in the study without risk of prejudicial treatment. It also means that participants have the right to ask questions, to refuse to give information, and to withdraw from the study (Polit & Beck, 2017:140).

Participants were given full information on the fact that participation is entirely voluntary and that they can withdraw from participating at any time. They were assured that there will be no repercussions or denial of services for withdrawing from participation in the study.

3.10.4 The right to privacy

This was achieved by storing the questionnaires in the researcher’s office, which has limited access, in a lockable cabinet. Names were not captured on the questionnaires; only numbers were used. All electronic data are being stored on a computer secured with passwords. To avoid loss of data, the researcher ensured availability of a backup system. An external hard drive, secured with a password, is being used to store the data. Informed consent forms are being stored in the researcher’s office, in the lockable cabinets. As mentioned, the office has limited access. Written and electronic data will be stored for five years after completion of the study.

3.11 Data analysis

It is essential when analysing data to provide statistical methods because they permit the researcher to reduce, summarise, organise, manipulate, evaluate, interpret and communicate quantitative data. Data were analysed using electronic software. The Statistical Package for the Social Sciences (SPSS) for Windows software, version 27, was used to enter the data from the completed questionnaires. Appropriate descriptive statistics such as frequencies, means, and standard deviations were used to describe the demographic and contextual variables as well as the level of SM.

For nominal and ordinal level data such as gender and the responses measured on a Likert-scale, frequency and percentage distribution tables or bar/pie charts were used to display the data. Continuous data was described by using measures of central tendency (mean or medial) or dispersion (standard deviation or interquartile range), depending on whether it was normally or non-normally distributed; histograms was used to visually display continuous data.

Inferential statistics use information from a sample to draw conclusions about the wider population from which the sample was collected. Because the purpose of inferential statistics to draw inferences from a sample and then generalise it for the entire population, it is critical that the sample accurately reflects the population (Gray et al, 2017:323).

Inferential statistics were performed with the assistance of a qualified biostatistician, using appropriate statistical tests, such as regression analysis, to determine the relationship between the independent variables (individual, environmental, and condition-specific factors) and the dependent variable (self-management). Regression analysis uses the statistics to examine how effectively one or more independent variables allow the researcher to predict the value of the dependent variable (Brink et al., 2012:191). For example, regression analysis was used to predict whether an independent variable, such as age, significantly increased or decreased SM scores in this sample. Multiple regression analysis was used to determine the effect of independent variables on the dependent variable (self-management) while controlling for other variables. Multiple regression analysis is a set of approaches for examining the relationship between a single continuous dependent variable and a number of independent variables (Pallant, 2016:149).

3.12 Conclusion

The methodology of the study, as well as the steps of the research process, were covered in this chapter. The study's design, population and sampling, instrumentation, data collection and analysis, and ethical considerations were presented in detail. The research results and interpretation of the data collected will be discussed in the following chapter.

CHAPTER 4

RESULTS

4.1 Introduction

The previous chapter included the discussion of the methodology used in this study as well as the ethical measures that were engaged to protect participants. The study results will be discussed in this chapter. Data analysis in quantitative research is used to reduce, organise, and give meaning to data (Grove & Gray, 2019:45). The data are presented using a descriptive statistical analysis in the form of frequency distribution tables, graphical presentations, and figures. To determine if there is a statistically significant relationship between the independent variables (contextual factors) and dependent variable (self-management), a p-value of ≤ 0.05 was used. Decimal numbers were rounded off to the first decimal.

4.2 Section 1: Background information

This section is a discussion of the participants' personal and family background including personal health information.

4.2.1 Personal and family information

This section included 26 questions about the youth living with HIV (YLWHIV), their family and their health. These questions pertained to the individual (age, gender) and family factors (family structure and functioning). All participants responded to the background information of the questionnaire (n=183).

There was 89.1% (n=163) females and 10.9% (n=20) males in the sample (Figure 4.1).

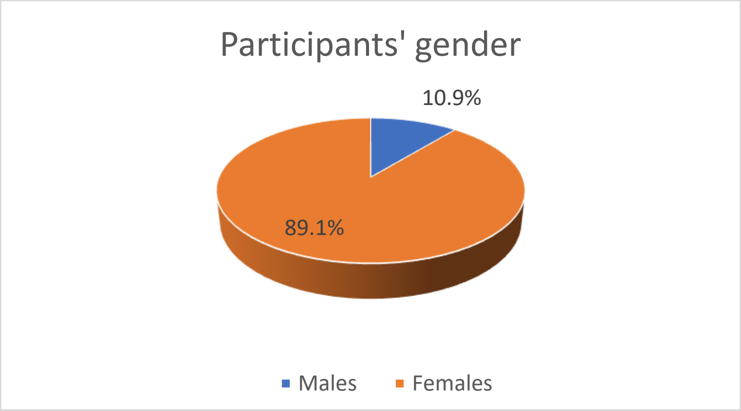


Figure 4.1: Gender

Table 4.1 shows the background information of the participants that were measured as ordinal or nominal level variables. Even though some respondents preferred the English version of the questionnaire, Sesotho was the first language of all the participants. Most of the participants were from the hospital (n=93; 50.8%), while 49.2% (n= 90) were from the health centre.

The median age was 22 (Interquartile range 4) and, when categorised, the majority of participants (61%; n=112), were between the ages of 21 and 24. About a third of the participants (29.5%, n=54) resided with other people than their family members. With regards to education, most of the participants (55.1%; n=101) indicated that they completed grades 10-12. Less than a fifth of the sample (19.1%; n=35) indicated that they completed tertiary education or were in a special school.

From the personal and family information, it can be deduced that most of the participants in this sample appeared to be older adolescents and youth with a level of education of grade 10 and above.

Table 4.1: Background information (nominal and ordinal variables)

Variable	Frequency (n)	Percentage (%)
Site		
Scott Hospital	93	50.8
Matelile Health Centre	90	49.2
Home language		
Sesotho	183	100
Gender		
Male	20	10.9
Female	163	89.1
With whom do you stay?		
Biological mother	41	22.4
Biological father	12	6.6
Biological father and mother	37	20.2
Family member (aunt, grandmother, sister, brother, etc.)	39	21.3
Other	54	29.5
Age		
15-17 years	31	16.9
18-20 years	40	21.8
21-24 years	112	61.2
School enrolment		
Yes	102	55.7
No	81	44.3
Completed educational grade		
6 – 9	45	24.5
10 – 12	101	55.1
Special school/tertiary	35	19.1
Your family: **How long have you lived with the person who looks after you?**		
Less than a year	3	1.6
1-5 years	46	25.1
6-10 years	21	11.5
More than 10 years	113	61.7
What is the level of education of the person who looks after you?		
Not sure	11	6.0
No formal schooling	2	1.1
Primary school	37	20.2
High school	67	36.6

Variable	Frequency (n)	Percentage (%)
College/ university	66	36.1
How many times have you moved from the house in the past 5 years?		
0	145	79.2
1	25	13.7
2	10	5.5
3	1	0.5
5	1	0.5
More than 5	1	0.5
Is your biological mother still alive?		
Not sure	1	0.5
Yes	126	68.9
No	56	30.6
Is your biological father still alive?		
Not sure	14	7.7
Yes	74	40.4
No	95	51.9
Are you in contact with your biological mother and father?		
Yes, with my mother and father	55	30.1
Yes, only with my mother	73	39.9
Yes, only with my father	15	8.2
No	40	21.9

With regards to **family stability**, almost two thirds of the participants (61.7%; n=113) had been living with the same caregiver for more than 10 years and 79.2% (n=145) had never moved in the past 5 years. The minority of participants (21.9%, n=40) had no contact with their biological mother or father. Most of the caregivers had either completed high school (36.6%; n=67) or tertiary education (36.1%; n=66).

4.2.2 Personal health information

This section contained questions about the young person's health, including their mental health. Health literacy was measured by asking whether they knew how they acquired HIV and what they understood about their CD4 count and viral load. The responses were mostly measured on a nominal level.

With regards to when they were **diagnosed** with HIV, 60.7% (n=111) indicated that it was at birth (Figure 4.2), although most (98.9% n=181) only learned about their status (were **disclosed** to) after the age of 12 (Table 4.2).

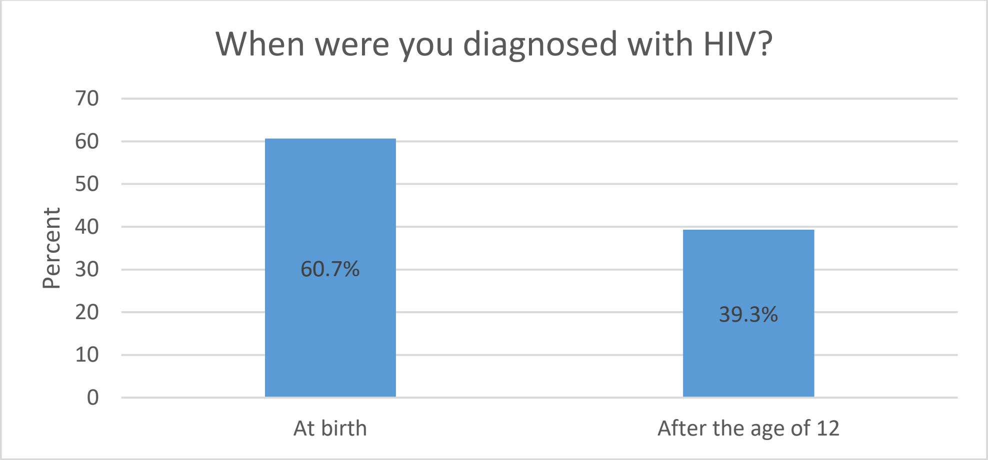


Figure 4.2: Age of diagnosis

With regards to their **health literacy**, the majority of participants (95.1%; n=174) did not have knowledge of their CD4 count, although 99.4% (n=182) reported that their viral load was undetectable (Table 4.2).

Concerning their **general health**, only two participants (1.1%) reported to have other conditions, which they indicated as diabetes. All the participants (100%; n=183) indicated that they were healthy.

When asked about the route of **HIV transmission**, most participants indicated that they acquired HIV through mother to child transmission (MTCT) (n=115; 62.8%), followed by having sex (n=62; 33.9%). Sadly, 7.1% (n=13) participants indicated that they acquired HIV through sexual abuse or forced sex. With regards to the **HIV trajectory**, the most probable route of infection was determined by the researcher and almost two thirds of the participants (62.3%; n=114) acquired HIV perinatally.

Table 4.2: Health information

Variable	Frequency (n)	Percentage (%)
When were you diagnosed with HIV?		
At birth	111	60.7
After the age of 12	72	39.3
At what age did you find out that you were HIV-positive?		
Between the ages of 10 and 12	2	1.1
After the age of 12	181	98.9
What is your most recent CD4 count? (Don't know)		
Yes	174	95.1
No	9	4.9
What is your most recent viral load? (Write down)		
Detectable	4	2
Undetectable	179	98
Do you have any other health conditions at the moment?		
Yes	2	1.1
No	180	98.4
Please mark the illnesses that you have		
Diabetes	2	1.1
No Illnesses	181	98.9
How did you become infected with HIV?		
At birth/from my mother (MTCT)		
Yes	115	62.5
No	69	37.5
How did you become infected with HIV? By having sex?		
Yes	62	33.9
No	121	66.1
Forced sex or abuse?		
Yes	13	7.1
No	170	92.9
Shared needles or recreational drug equipment?		
No	183	100
Blood transfusions or other medical procedure?		
No	183	100
Most probable route of infection (Researcher determined)		
Perinatally	114	62.3
Behaviourally	69	37.7
How would you rate your own health?		

Variable	Frequency (n)	Percentage (%)
Healthy	183	100
During the past 12 months, have you felt the following for 2 weeks in a row? Sad, angry or depressed		
No	182	99.5
Yes	1	0.5
During the past 12 months, have you felt the following: That you lost interest in most things that usually give you pleasure?		
No	183	100
During the past 12 months, have you felt the following: Worried or anxious most of the time?		
No	182	99.5
Yes	1	0.5

With regards to mental health, none of the participants reported that they have lost interest in things that usually gives them pleasure over the past 12 months (Table 4.2). Almost all of the participants (99.5%; n=182) said that they have never felt anxious over the past 12 months, while only one participant (0.5%; n=1) indicated that they had been worried and anxious most of the time. A mental health score was created by calculating the sum of the three mental health questions. The mean was 0.01 (SD 0.1).

From the personal health information, it can be deduced that most of the participants in the sample acquired HIV perinatally, that they were generally healthy, had few comorbidities, are virologically suppressed, and have very little mental health problems. However, very few participants had knowledge of their CD4 count. Information about the participants' viral load was verified by the researcher by reviewing their clinical records. Four participants had a detectable viral load, but it was below 1000 copies/ml.

4.3 Section 2: Their treatment

This section included 9 questions about the antiretroviral treatment the adolescent (nominal level measurement) is taking and their adherence to treatment (ordinal level measurement). These questions pertain to the **condition-specific factors**.

The participants were all on treatment (Table 4.3). Most of the participants (81.4%; n=149) have been on treatment for more than 10 years, followed by 10.9% (n=20) who have been on treatment between 1-5 years. Nine participants (4.9%; n=9) have been on treatment between 6-10 years and 2.7% (n=5) have been on treatment for less than a year (Figure 4.3).

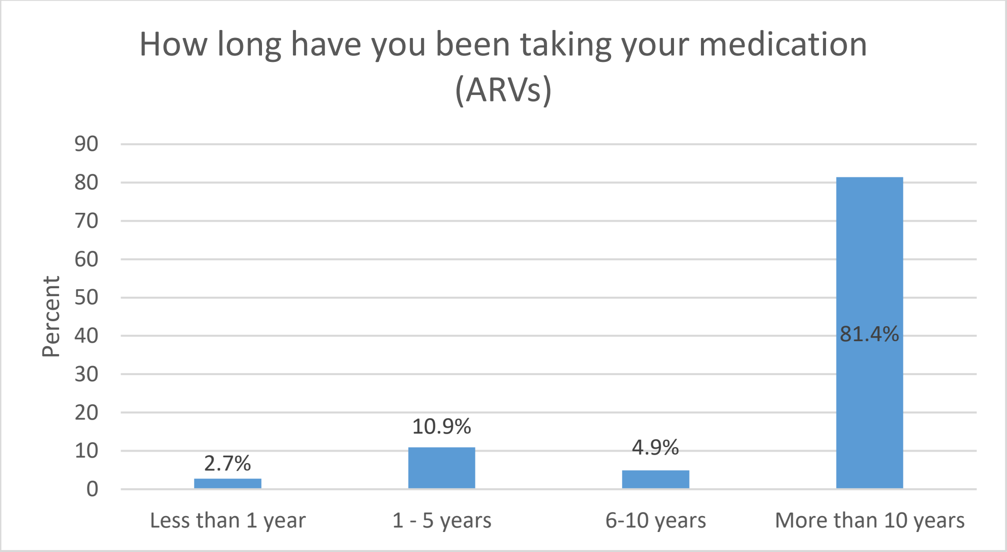


Figure 4.3: Time on treatment

Regarding the type of **regimen** and **frequency of treatment**, all the participants indicated that they were taking one tablet once a day. The regimen includes the following antiretroviral therapy (ART) medications provided in a fixed-dose combination: Tenofovir (TDF), Lamivudine (3TC) and Dolutegravir (DTG), which is a first line regimen (Table 4.3).

With regards to **adherence**, almost all the participants (98.9%; n=181) indicated that they never missed a dose of their antiretrovirals (ARVs) and none of the participants had ever stopped their treatment. Clinic attendance was confirmed by reviewing the clinic folders which revealed that none of the participants had missed a clinic appointment in the last 6 months.

A client with a viral load of below 1000copies/ml is said to be virologically suppressed. All patients were therefore, virologically suppresed as evidenced by viral load values lower than 1000copies/ml (n=179; 98 %). According to the Government of Lesotho (2016:2), a viral load of below 1000copies/ml is suppressed. Participants in this sample were on first line combination treatment with above average adherence and viral suppression rates.

Table 4.3: The participants' treatment

Variable	**Frequency (n)**	**Percentage (%)**
Which of these three choices describes you best?		
I am taking ARVs at the moment	183	100
How long have you been taking your medication (ARVs)?		
Less than 1 year	5	2.7
1-5 years	20	10.9
6-10 years	9	4.9
More than 10 years	149	81.4
How many tablets do you take every day?		
1	183	100
How often do you take your tablets?		
Once a day (evening only)	183	100
In general, over the past month, how often did you miss taking your ARVs?		
In ever miss any of my ARVs	181	98.9
I miss my ARVs a little bit of the time	2	1.1
What month and year did you miss taking your ARVs?		
Never stopped	183	100

4.4 Section 3: Their hospital or clinic

This section included 5 questions about the adolescents' satisfaction with healthcare services, adolescent-friendly services, and transportation. These questions relate to the **physical and environmental factors** and was measured on a nominal level (yes / no).

The participants' overall perception was that they were either always (n=126; 68.9%) or usually (n=57; 31.1%) treated with respect. The majority were very satisfied (n=111; 60.7%), (n=68; 37.2%) were satisfied with the services at the clinic or hospital (Figure 4.4).

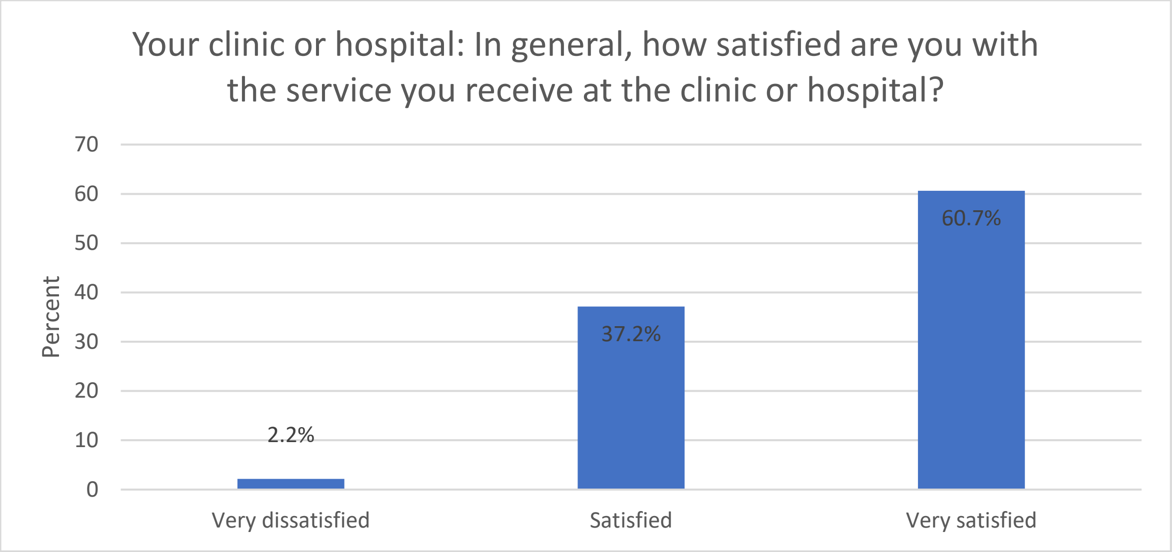


Figure 4.4: Satisfaction level with services offered

Transportation problems sometimes prevented more than two thirds of the participants (69.9%; n=128) from attending appointments, while about a third (30.1%; n=55) never encountered problems with transportation (Table 4.4).

Table 4.4: Participants' clinic/hospital

Variable	Frequency (n)	Percentage (%)
My health provider treats me with respect		
Usually	57	31.1
Always	126	68.9
In general, how satisfied are you with the services you receive at the clinic/hospital?		
Very dissatisfied	4	2.2
Satisfied	68	37.2
Very satisfied	111	60.7
Do you like going to the clinic/hospital?		
Yes	183	100
Do transport problems prevent you from going to the clinic/ hospital?		
Never	55	30.1
Sometimes	128	69.9

The satisfaction with services score was created by adding the questions related to being treated with respect and satisfaction with services. The mean score was 5.3 (SD 0.95), with a minimum of 3 and a maximum of 6 (Figure 4.5).

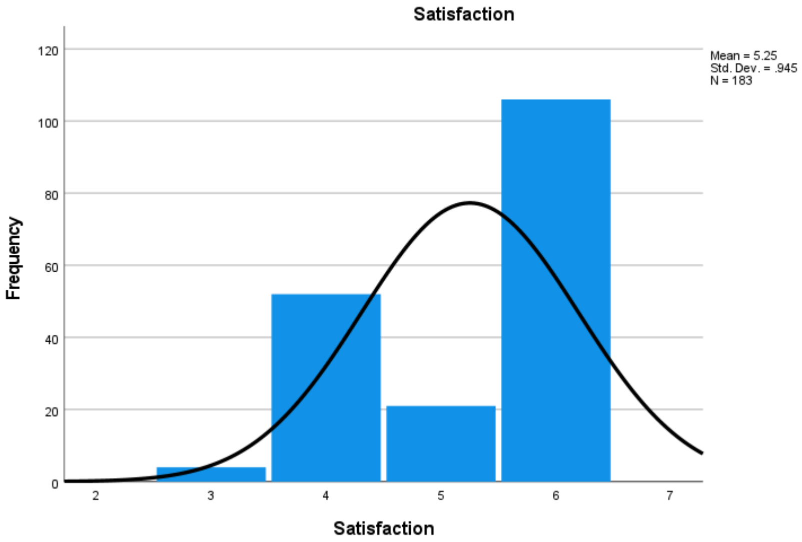


Figure 4.5: Histogram of satisfaction with services score

Section 4: Self-management

This section included 44 items that measured self-management (SM). The Adolescent HIV Self-Management Scale (AdHIVSM) has been developed in South Africa and has high validity and reliability (Crowley, 2018). The questions were measured on a Likert-type scale from ‘strongly disagree / never = 1’ to ‘strongly agree / always = 4’. Some items were negatively phrased and inversely coded.

The item mean scores for many of the items were above 3.9, indicating good SM related to **beliefs and knowledge** (Table 4.5a). Items in which participants had the lowest mean SM scores included:

- Knowing when to contact the doctor or nurse (mean 1.31; SD 0.62),
- Telling someone if they are being bullied (mean 3.75; SD 0.47), and
- Knowing the names of the ARVs (mean 3.70; SD 0.58).

Table 4.5a: Self-management part A

Variable	Strongly disagree n (%)	Disagree n (%)	Agree n (%)	Strongly agree n (%)	Mean (SD)
1. I know the signs and symptoms of my illness (HIV) (for example, when I am sick or have side-effects from my ARVs	0	0	2 (1.1)	181 (98.9)	3.99 (0.1)
2. I can get information about HIV	1 (0.5)	0	2 (1.1)	180 (98.4)	3.97 (0.24)
3. I know the date of my next hospital or clinic appointment	3 (1.6)	1 (0.5)	3 (1.6)	176 (96)	3.92 (0.43)
4. I know how to contact the doctor or nurse if I need to	138 (75.4)	39 (21.3)	1 (0.5)	5 (2.7)	1.31 (0.62)
5. I can achieve as much as other people who don't have HIV	0	0	19 (10.4)	164 (89.6)	3.90 (0.30)
6. My faith helps me to stay positive about myself and my future	1 (0.5)	0	9 (4.9)	173 (94.5)	3.93 (0.31)
7. I am confident that I can take care of my health	0	0	8 (4.4)	175 (95.6)	3.96 (0.21)
8. I would cope if I told someone about my HIV status and that person didn't accept it or ignored me	0	1 (0.5)	4 (2.2)	178 (97.3)	3.97 (0.21)
9. I would tell my parents or teacher if I were being bullied (physically or verbally) and it felt out of control	1 (0.5)	0	42 (23.0)	140 (76.5)	3.75 (0.47)
10. I decide by myself whom I want to tell about my HIV status	1 (0.5)	1 (0.5)	15 (8.2)	166 (90.7)	3.89 (0.38)
32. I understand why I am taking ARVs	0	0	27 (14.8)	156 (85.2)	3.85 (0.36)
33. I know the names of ARVs	1 (0.5)	9 (4.9)	33 (18.0)	140 (76.5)	3.70 (0.58)
34. I know at what times I should take my ARVs	2 (1.1)	9 (4.9)	33 (18.0)	140 (76.5)	3.81 (0.48)
35. I know what to do when I miss the time to take my ARVs	0	0	29 (15.8)	154 (84.2)	3.84 (0.37)
36. I understand what will happen if I don't take my ARVs every day	0	0	30 (16.4)	153 (83.6)	3.84 (0.37)
37. I know what my viral load is	1 (0.5)	3 (1.6)	33 (18.0)	146 (79.8)	3.77 (0.49)
38. I know what my viral load should be	2 (1.1)	2 (1.1)	32 (17.5)	147 (80.3)	3.77 (0.49)

Table 4.5 (a) With regards to SM skills, participants indicated lower scores in the aspects of coping with HIV-related stigma (mean 3.55; SD 0.49); practicing positive coping strategies (mean 3.51; SD 0.56); having confidence to meet their health and life goals (mean 3.55; SD 0.56); and having healthy habits (mean 3.55; SD 0.52). Over half of the participants (55.7%; n=102) indicated that they aim for independence most of the time, but not always.

With regards to participating in their healthcare, lower scores were observed in:

- Taking part in decisions about their health (mean 3.33; SD 0.66);
- Communicating with the doctor or nurse about private things (mean 1.36; SD 0.77) or if they missed medication doses (mean 3.08; SD 0.50).

Participants in general did not think they will be able to access community resources (mean 1.54; SD 0.81) and did not feel supported by peers at the clinic (mean 1.77; SD 0.98). They also did not have regular contact with other friends (mean 2.92; SD 0.73) and tended to not participate in school activities (mean 2.22; SD 0.76). With regards to treatment taking behaviour, the majority (97.3%, n=178) indicated that they sometimes did not take treatment when they did not feel like it. Although only 105 participants answered the question about condom use, only one participant (0.5%) indicated that he/she always used a condom.

Table 4.5b: Self-management part B

Variable	Never n (%)	Sometimes n (%)	Most of the time n (%)	Always n (%)	Mean (SD)
11. I can cope with it if people say nasty or hurtful things about people living with HIV	0	0	82 (44.8)	101 (55.2)	3.55 (0.49)
12. Doing things I like (for example listening to music, reading or playing sport) helps me to cope	1 (0.5)	3 (1.6)	80 (43.7)	99 (54.1)	3.51 (0.56)
13. Things like eating junk food, smoking cigarettes, drinking alcohol or taking drugs help me to cope (R)	182 (99.5)	0	0	1 (0.5)	3.98 (0.22)
14. I am to be independent (taking care of myself)	3 (1.6)	0	102 (55.7)	78 (42.6)	3.39 (0.58)
15. I aim to enjoy life, feel good and have fun	0	0	49 (26.8)	134 (73.2)	3.73 (0.44)
16. I aim to be successful (for example, finishing school, studying further or getting a job)	0	1 (0.5)	67 (36.6)	115 (62.8)	3.62 (0.49)
17. I feel confident that I can meet my health and life goals	0	6 (3.3)	70 (38.3)	107 (58.5)	3.55 (0.56)
18. I do things to improve my health (for example, by exercising or eating healthy foods)	0	2 (1.1)	79 (43.2)	102 (55.7)	3.55 (0.52)
19. I attend clinic appointments on my own	0	0	53 (29.0)	130 (71.0)	3.71 (0.45)
20. I attend clinic appointments on scheduled dates (for example, I use a calendar, phone or my clinic card to remind myself)	0	0	35 (19.1)	148 (80.9)	3.81 (0.39)
21. I take part in decisions about my health and treatment (for example, I tell the doctor or nurse what I think and we make decisions together)	1 (0.5)	17 (9.3)	86 (47.0)	79 (43.2)	3.33 (0.66)
22. I ask the doctor or nurse questions when there is anything I don't understand	0	13 (7.1)	80 (43.7)	90 (49.2)	3.42 (0.62)
23. I tell the doctor or nurse how I am feeling (for example, when I feel sick, depressed or have side-effects because of my treatment)	1 (0.5)	20 (10.9)	76 (41.5)	86 (47.0)	3.35 (0.69)
24. I tell the doctor or nurse when I miss a dose of my ARVs	1 (0.5)	13 (7.1)	139 (76.0)	30 (16.4)	3.08 (0.50)
25. I tell the doctor or nurse about private things (for example, if I am having sex or using drugs or alcohol)	144 (78.7)	19 (10.4)	13 (7.1)	7 (3.8)	1.36 (0.77)
26. My family supports me to live with HIV	0	1 (0.5)	18 (9.8)	164 (89.6)	3.89 (0.78)

Variable	Never n (%)	Sometimes n (%)	Most of the time n (%)	Always n (%)	Mean (SD)
27. The doctors, nurses and counsellors at the clinic support me to live with HIV	4 (2.2)	2 (1.1)	83 (45.4)	94 (51.4)	3.46 (0.64)
28. Other adolescents at the clinic (for example, in my support group or club) support me to live with HIV	99 (54.1)	42 (23.0)	28 (15.3)	14 (7.7)	1.77 (0.98)
29. I have regular contact with my friends (for example, at school or in my community)	6 (3.3)	38 (20.8)	104 (56.8)	35 (19.1)	2.92 (0.73)
30. I participate in activities at school or in my community	21 (11.5)	117 (63.9)	29 (15.8)	16 (8.7)	2.22 (0.76)
31. I would find help in my community if I needed it (for example, a social worker if I had problems at home or at school	116 (63.4)	42 (23.0)	19 (10.4)	6 (3.3)	1.54 (0.81)
39. I rely on other people to remind me to take my ARVs	183 (100)	0	0	0	4.00 (0.00)
40. Other things interfere with my plans to take ARVs (For example, when I go to a party or sleepover when I do drugs)	183 (100)	0	0	0	4.00 (0.00)
41. I plan how to take my ARVs when I am not at home (for example, when I am out with friends or go on a school camp)	0	0	1 (0.5)	182 (99.5)	3.99 (0.74)
42. I aim to understand why my viral load is high or low	0	0	0	183 (100)	4.00 (0.00)
43. I take my ARVs even when I don't want to (for example, when I feel depressed or am tired of taking them)	0	178 (97.3)	5 (2.7)	0	2.03 (0.16)
44. My partner and I use a condom	8 (4.4)	55 (30.1)	41 (22.4)	1 (0.5)	2.33 (0.63)

A total SM score was calculated with the sum of the items 5, 7, 8, 10, 11, 12, 14, 15, 18, 20, 22, 29, 32, 33, 34, 35, 36, 37, 38, 41 divided by 80 as explained in chapter 3. The mean score was 92.7% (SD 5.3%). The minimum score was 76% and the maximum 100% (Figure 4.6).

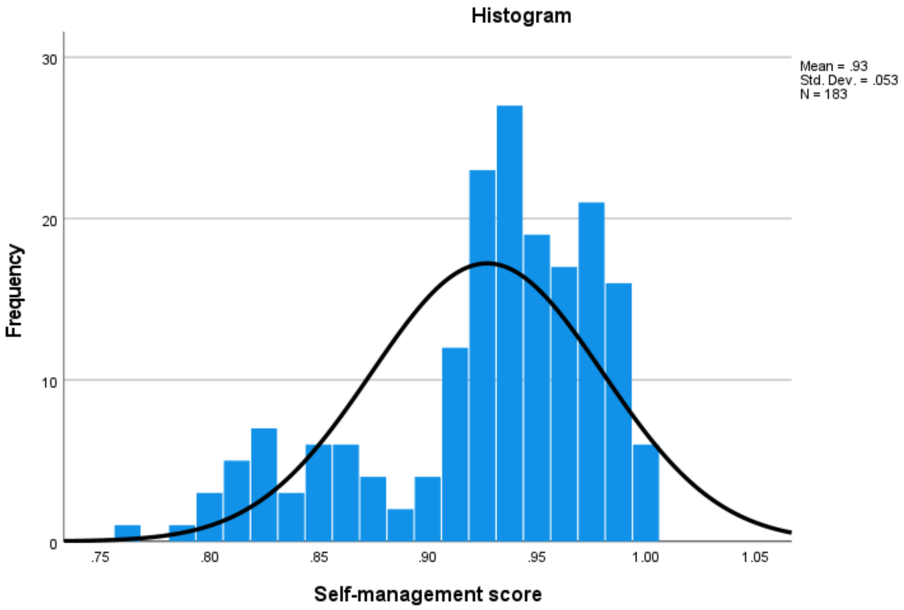


Figure 4.6: Histogram of self-management score

4.6 Section 5: Strengths and difficulties

This section contained 25 questions measuring the strengths and difficulties using a standardised questionnaire. The Strengths and Difficulties Questionnaire (SDQ) provides information about **individual factors.** Although the participants reported strengths in that they certainly cared about others (100%; n=183); shared with others (food, toys,(98.4%; n=180); were helpful when others are upset (100%; n=183); was kind to younger children and volunteered to help (97.3%; n=178); only 73.2% (n=134) indicated that they had one good friend. Almost five percent (4.9%; n=9) of participants reported that they are nervous in new situations and that they easily lose confidence (Table 4.6).

Table 4.6: Strengths and difficulties

Variable	Not true n (%)	Somewhat true n (%)	Certainly true n (%)
I try to be nice to other people. I care about their feelings.	0	0	183 (100)
I'm restless, I can't stay still for long.	171 (93.4)	10 (5,5)	1 (0.5)
I get a lot of headaches, stomach aches or other sicknesses.	172 (94.0)	10 (5.5)	1 (0.5)
I usually share with others (food, games, pens etc).	1 (0.5)	2 (1.1)	180 (98.4)
I get very angry and often lose my temper.	182 (99.5)	1 (0.5)	0
I am usually on my own. I play alone or keep to myself.	182 (99.5)	1 (0.5)	0
I usually do as I am told.	0	0	183 (100)
I worry a lot.	177 (96.7)	6 (3.3)	0
I am helpful when someone is hurt, upset, or feeling ill.	0	0	183 (100)
I am fidgeting or squirming.	183 (100)	0	0
I have one good friend or more.	5 (2.7)	44 (24.0)	134 (73.2)
I fight a lot. I can make other people do what I want.	183 (100)	0	0
I am often unhappy, downhearted or tearful.	182 (99.5)	1 (0.5)	0
Other people my age generally like me.	7 (3.8)	64 (35.0)	112 (61.2)
I am easily distracted. I find it difficult to concentrate.	180 (98.4)	3 (1.6)	0
I am nervous in my new situations. I easily lose confidence.	174 (95.1)	9 (4.9)	0
I am kind to younger children.	2 (1.1)	3 (1.6)	178 (97.3)
I am often accused of lying or cheating.	181 (98.9)	1 (0.5)	1 (0.5)
Other children or young people pick on me or bully me.	182 (99,5)	1 (0.5)	0
I often volunteer to help others (parents, teachers, children etc.).	2 (1.1)	3 (1.6)	178 (97.3)
I think before I do things.	0	0	183 (100)
I take things that aren't mine from home, school or elsewhere.	181 (98.9)	1 (0.5)	1 (0.5)
I get on better with adults than with people my own age.	148 (80.9)	28 (15.3)	7 (3.8)
I have many fears. I am easily scared.	182 (99.5)	1 (0.5)	0
I finish the work I am doing. My attention is good.	1 (0.5)	0	180 (98.4)

The total difficulties score had a mean of 1.26 (SD 1.7), minimum 0 and maximum 11. The strength score had a mean of 9.9 (SD 3.8), minimum 8 and maximum 10. This indicates that most participants reported several strengths and few difficulties

4.7 Regression analysis of factors influencing self-management

A regression analysis of the factors that influence SM was performed. Firstly, regression analysis was performed for each of the independent variables on the dependent variable. The individual analyses are not shown here. The biostatistician included independent variables that showed a level of significance of $p \leq 0.1$ in the multiple regression model.

When the factors were included in the multiple regression model, higher levels of SM are predicted with the **individual variable** of disclosure (the age of disclosure being after the age of 12 compared to between 10 and 12). However, the mean difference between the SM scores of the groups was only 0.088 (p=0.02). Only two participants reported to have their status disclosed to them between 10 and 12; the rest were disclosed to after the age of 12 (n=181).

Self-management increased by 0.032 units with every one unit increase in the **individual** Strength score ($p < 0.01$) and SM decreased with 0.074 units with every one unit increase in the Mental Health score ($p < 0.05$).

The SM scores increased with the **condition-specific** variable of duration on treatment. Participants who were on treatment for 6 to 10 years and more than 10 years had significantly higher SM scores compared to those on treatment for 1 to 5 years (p=0.02 and p=0.01).

The **environmental** variable of sometimes having transport problems compared to never having transport problems was associated with higher SM, although the difference between groups was only 0.029 units. The finding of transport problems increasing SM scores is interesting and requires further exploration. Most participants reported to sometimes experiencing transport problems (n=128; 69.9%).

The other variables lost significance in the regression model. The model predicted 29.3% (Adjusted R squared) of the variance observed in the SM score. This means that there may still be several other factors that may explain the variation in SM of YLWHIV that was not included in this model.

Table 4.7: Regression analysis

Dependent variable: Self-management score (n=181)				**(Adjusted R^2= 0.293)**
	Coef.	**p value**	**95% Confidence Interval**	
Site: Health Centre (1=hospital; 2=health centre)	-0.008	0.31	- 0.024	0.007
Individual: family stability - times moved house in the past 5 years	0.001	0.24	-0.008	0.011
Individual: Age of disclosure (2=10 to 12; 3=after 12)	0.088	0.02	0.016	0.159
Individual: Health literacy – Don't know CD4 count (1=yes; 2=no)	-0.015	0.43	-0.050	0.021
Condition: trajectory (1=perinatal; 2=behavioural)	0.003	0.74	-0.015	0.021
Condition duration: 1=less than 1 year				
2=1 – 5 years	0.040	0.08	-0.005	0.093
3=6-10 years	0.069	0.02	0.012	0.125
4=>10 years	0.078	0.01	0.027	0.129
Environment: Transport (0=never; 1=sometimes)	0.029	<0.01	0.013	0.045
Strengths score	0.032	<0.01	0.013	0.052
Difficulties score	-0.003	0.280	-0.008	0.002
Mental health score	-0.074	<0.05	-0.147	-0.001
Constant	0.652	0.000	0.414	0.889

4.8 Conclusion

In this chapter, the finding of the study on factors influencing SM in YLWHIV were discussed. Tables and graphs were used to present the data, which were supported by explanations. The data were analysed using the SPSS version 27 software. The study's objectives were all met. The findings will be addressed in the next chapter considering the study's objectives, and recommendations will be made where needed.

CHAPTER 5

DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS

5.1 Introduction

In the previous chapter, the analysed data and results obtained from the sample of 183 youth living with HIV (YLWHIV) accessing HIV care at Scott Hospital and Matelile Health Centre were presented. The current chapter will establish whether the results obtained in this study are consistent with or contradictory to findings from other studies carried out in the past locally, regionally, and globally.

The rationale for this study, as well as the setting in which it was conducted, were outlined in Chapter 1. Chapter 2 included a comprehensive review of the factors influencing self-management (SM) amongst YLWHIV. The focus of chapter 3 was on the methodology, while chapter 4 focussed on data analysis and interpretation. Finally, in this chapter, the results are discussed to inform the conclusions and recommendations. The study's limitations are also explored.

5.2 Discussion

Before the discussion of the study objectives, the researcher will first present a summary of the findings related to the background information of the participants and their SM.

5.2.1 Background characteristics of YLWHIV

In accordance with the study conducted by Mbokazi, Madzima, Leon, Lurie, Cornell, Schmidt et al. (2020:5), it is argued that African men generally fare worse than women across the HIV treatment cascade; they tend to access HIV prevention and treatment services less than women. Keenly fascinating, the study population mainly comprised female respondents (89.1%; n=163) and their male counterparts accounted for the remaining percentage (10.9%; n=20). In Lesotho, there are fewer males accessing HIV treatment (76.6%) versus females (84%) (Government of Lesotho, 2016:1).
The median age was 22, when categorised 61.2%, which means that almost two thirds of the participants were between 20 and 24. Therefore, this sample included older

YLWHIV who may be ready for or in the process of transitioning to adult care. Older adolescents are more prepared and ready for transition into adult care, as they become increasingly independent, and they can continue to take good care of themselves and follow through on the tasks that keep them healthy (Sharer et al., 2014:10).

5.2.2 Self-management

The original Adolescent HIV Self-Management Scale (AdHIVSM-35) developed for adolescents aged 13-17 in the Western Cape, South Africa (Crowley, 2018), had low reliability measures for the subscales, except for the biomedical management subscale. During analysis, items that lowered the reliability of the scale were removed and an exploratory factor analysis performed to explore the factor structure of the SM scale amongst this age group (adolescents living with HIV aged 15-24 in Lesotho).
The factor structure for SM in this age group related to roles, and emotional and medical self-management. This is similar to the earlier work on SM conducted by Lorig and Holman (2003:1). It is stated that SM consists out of three tasks, which are the medical, roles and emotional SM. In the present study, the scale on medical management had the highest factor loadings. Also, the biomedical management subscale was the only reliable subscale of the original AdHIVSM-35. This may mean that medical management is the primary focus of SM amongst adolescents living with HIV (ALWHIV) in this sample. This is congruent with a systematic review on SM interventions for young people with chronic conditions that found that there is a great focus on medical management, neglecting other areas such as emotional and psychosocial management (Sattoe et al., 201:710).

In this study, adolescents generally had very high SM scores. The item mean scores for many of the items were above 3.9, indicating good SM across the domains**.** The items where participants had high mean SM scores are:

- Knowing the signs and symptoms of their illness and when they have side effects of the antiretrovirals (ARV) (Mean 3.99; SD 0.1)
- Never using things like alcohol, eating junk food, smoking cigarettes or taking drugs in order to cope (Mean 3.98; SD 0.22)
- Getting information about HIV (Mean 3.97; SD 0.24)

- Being able to cope if they told someone about their HIV status and that person ignored them (Mean 3.97; SD 0.21)
- Being confident to take care of their own health (Mean 3.96; SD 0.21)
- Knowing the date for the next appointment (Mean 3.81; SD 0.39).

The results are similar to a study conducted in South Africa by Crowley et al. (2020:7) that found adolescents aged 13-17 generally had good SM with item means of more than 3. However, in the present study, items consistently had higher SM mean scores when compared to the South African study. This may be because these were older adolescents and youth.

The high scores corresponded well with the treatment outcomes of the participants. For example, all of the participants were virologically suppressed (defined as a viral load of <1000 copies per ml). Similarly, almost all the participants (98.9%; n=181) indicated that they never miss a dose of their treatment. The viral load suppression in this study is higher compared to the viral load suppression rates reported in the study conducted in Cape Town, South Africa amongst 13–17-year-old ALWHIV. In that study the viral load suppression rates were 80.56% (Crowley et al., 2020: 7). This study's results are much higher than a study conducted in the Eastern Cape of South Africa where they found that only 47.5% of the sample (median age of 13) were virally suppressed at the most recent test (Haghitat,Toska, Bungane, & Cluver, 2021:4). This may mean that older adolescents and youth have better adherence and, consequently, higher viral suppression rates compared to younger adolescents.

Another reason for the high SM scores and above average adherence and viral suppression rates could be the context in which these adolescents receive care. The context in which the care is provided may motivate YLWHIV to attend health services. The services at the two study sites were generally youth-friendly health services, which youth can access at the time when they need to and at affordable costs. Waiting periods at these services are also not long, so youth may become motivated to attend (Government of Lesotho, 2017:11).

Although the participants, in general, had high scores on the various SM items, certain items had low scores. These items had scores below 3 and some below 2 and included:

- Having regular contact with friends (for example, at school or in the community) (Mean 2.92; SD 0.73)
- Using a condom at the last sexual encounter (Mean 2.33; SD 0.63)
- Participating in activities at school or in their community (Mean 2.22; SD 0.76)
- Taking ARVs even when they do not want to (for example, when they feel depressed or are tired of taking them) (Mean 2.03; SD 0.16)
- Support received by other adolescents at the clinic (for example, in their support group or club) (Mean 1.77; SD 0.98)
- Finding help in the community if needed (for example, a social worker if they had problems at home or at school) (Mean 1.54; SD 0.81)
- Communicating about private things to a doctor or nurse (Mean 1.36; SD 0.77)
- Knowing when to contact the doctor or nurse (Mean 1.31; SD 0.62).

The low scores in the abovementioned items may mean that the items are not relevant to the age group or within the context. However, it may also identify areas where the participants require SM support.

The lack of friends/community involvement is usually seen in this age group, as they are a group that faces various emotional and psychological challenges. They sometimes feel uncomfortable to mingle with peers if they have not disclosed their status to their friends. In addition, they fear rejection by community members (Xu et al., 2017:2). It is interesting that they do not feel supported by peers at the clinic as peer groups are seen as a good source of support. Studies indicate that participating in peer-based groups improves adherence, retention in treatment, and viral suppression (UNICEF, 2021:8).

Condom use may be compromised in this age group, as adolescence is a unique stage in life. It is a critical stage of physical, cognitive, and emotional development for teenagers, and it has an impact on how they perceive themselves and their surroundings. These changes have an impact on their attitudes, decision-making abilities, and risk assessment skills, as well as their behaviour (Armstrong et al., 2017:6). It is evident that 57.3% of the participants are sexually active as they responded to the question about condom use. However, the SM item about consistent condom use had a low mean score. Some adolescents may not feel like taking ARVs when they do not want to. Reluctance to take treatment may be due to having had long-term ART leading to treatment fatigue (Armstrong et al., 2017:7).

In general, although the SM scores are high, participants seem to have lower scores in relational components (interactions with friends, peers and healthcare workers), which is important for their transitioning to adult care, accessing resources in the community, and negotiating condom use with partners to prevent HIV transmission. Finding help in the community and participating in the community are other areas where participants had lower SM scores. Youth are generally a population with different SM needs and challenges (Mutumba et al., 2019:2).

The specific study objectives are discussed below with reference to the analysis in chapter 4 and the relevant literature.

5.2.3 Objective 1: Establish condition-specific factors influencing self-management

Condition-specific factors influencing SM include the type of medication, frequency thereof, their general health, and illness trajectory.

With regards to the **type of medication/regimen and frequency of treatment**, the study found that most youth take only one tablet once a day in the evening. This factor contributes to improved SM due to the lower pill burden (Schulman-Green et al., 2012:140). In this sample, adolescents had above average adherence and viral suppression rates, which could be attributed to the low pill burden.
Schulman-Green et al. (2012:140) point out that significant factors influencing SM are pill burdens and the frequency with which the medication is taken. If the youth have more medications to take at the same time, it becomes a burden and the youth become demoralised by the many pills that that they need to take (Sharer & Fullem, 2012:11). Adherence to ART is negatively affected by how difficult it is to follow the prescribed regimen.

With regards to the **HIV trajectory**, the most probable route of infection was determined by the researcher and almost two thirds of the participants (62.3%; n=114), acquired HIV perinatally while 37.7% (n=69) of the participants acquired HIV behaviourally. Most participants (81.4%; n=149) in this sample have been on treatment for more than 10 years. Further, most of the participants in this sample reported to have good health with few comorbidities. Given the high percentage of perinatally infected adolescents, it would be expected that some may be on second line treatment, however, all the participants were on a first line regimen.

Adolescents who acquire HIV perinatally may have long-term experience with ART with side effects and they may experience treatment fatigue. In addition, they may also be on second- or third-line treatment due to treatment failure. Lastly, they may have a history of illness and frequently attend hospital or clinics (Armstrong et al., 2019:7).
In this study, SM scores increased with the **condition-specific** variable of duration on treatment. Participants who were on treatment for 6 to 10 years and more than 10 years had significantly higher SM scores compared to those on treatment for 1 to 5 years (p=0.02 and p=0.01). These results may be because some adolescents may have acquired SM skills over time (Iribarren et al., 2019:7).

The illness trajectory was also significantly associated with SM scores, although it lost significance in the regression model. Adolescents who acquired HIV perinatally had slightly higher mean SM scores (mean=93.5) compared to those who acquired HIV behaviourally (mean=91.5) (Mann-Whitney U, p=0.03). According to the literature, adolescents who have acquired HIV perinatally may have been on treatment for longer and, since SM follows the youth's developmental trajectory, it is the assumption that at a certain age they may have mastery of SM activities (Lozano & Houtrow, 2019:s238).

5.2.4 Objective 2: Ascertain the physical and social environmental factors influencing self-management

The physical and social environmental factors include access to treatment and adolescent-friendly services. Access to treatment means that the youth can get treatment and other healthcare services at all times when the need arises (Haghitat, Dreyer & Roos, 2010:30).

When it came to accessing treatment, the majority of participants (69.9%; n=128) admitted to having occasional transportation challenges. Although they sometimes experience transport problems, the researcher has observed that they may still be able to get to the health facility as there is also a system in Lesotho where support buddies can bring treatment for other buddies, especially if they have good adherence and viral suppression. Access to health services means that the services are geographically, functionally, financially and culturally acceptable and accessible to the youth (Hattingh, Dreyer & Roos, 2008:30).

The environmental variable of **sometimes having transport problems** compared to never having transport problems was associated with higher SM, although the difference between groups was only 0.029 units. The finding of transport problems increasing SM scores is interesting and requires further exploration. The literature indicates that lack of dependable transportation can be a barrier to obtaining and engaging in health services for disadvantaged populations such as older adults, minorities, low-income individuals, and those with disabilities (Ruggiano, Shtompel, Whiteman & Sias, 2017:62).

With regards to **adolescent-friendly services**, all the participants (100%) reported that they enjoy going to the health facilities. The majority (68.9%; n=126) indicated that they are always treated with respect at the health facilities, while 31.1% (n=57) indicated that they are usually treated with respect while attending health services. Being respected promotes utilisation of services and, consequently, SM (Government of Lesotho, 2017:11).

The SM scores of the participants differed slightly across the two treatment sites (93.5 at the healthcare centre and 91.9 at the hospital), although this difference was not significant and scores were high in both groups. The services at the two sites are not very different; however, the participants from the health centre were older youths with more SM abilities. ART services for youth are accessible in a manner that motivates them to attend, which minimises missed clinic appointments and non-adherence; hence, SM is improved (Vasuthevan & Mthembu, 2014:40). Specifically, in the study context, ART services are provided in secluded buildings identified as the youth corners. At Matelile Health centre, ART services for the youth and adults are accessible on the same premises.

Within Scott Hospital, there are youth corners where services are tailor-made to respond to the different needs of youth. Trained personnel offer the specialised services to the youth. These services may have motivated youth to attend services, as reflected in this study. Attending services is a positive indicator of good SM behaviours (Gage et al., 2017:8).

At Scott Hospital, there are special days selected for youth to meet and interact with one another and share experiences about their condition. The majority of the youth also indicated that they never miss hospital and clinic appointments. This affirms that the youth are motivated by the services they receive.

Generally, the participants in this study were satisfied with the services they received. The satisfaction with services score was created by adding the questions related to being treated with respect and satisfaction with services. The mean score was 5.3 (SD 0.95), with a minimum of 3 and a maximum of 6. SM is promoted and improved when clinic attendance is good, because health workers emphasise and monitor good health practices (Pike et al., 2020:2).

The government should sponsor the facilities that have youth-friendly services with resources and youth-friendly materials such as posters and even televisions. These could attract more youth to seek health services because they are kept engaged while waiting in the waiting area.

5.2.5 Objective 3: Determine individual and family characteristics influencing self-management

Individual and family SM includes incorporating health-related behaviours into a person’s or family’s day to day operation. Individual or family SM prevents or attenuates illness or facilitates the management of complex health regimens in ways that reflects individual or family values in personally meaningful ways (Sawin, 2017:173). Individual and family characteristics include the age of the adolescent, psychological strengths and difficulties, as well as health literacy.

5.2.5.1 Individual factors

With regards to **age**, it was deduced that most of the participants in the sample appeared to be older adolescents and youth with a level of education at grade 10 and above. Chao et al., (2014:2) points out that one of the characteristics of older adolescence is eagerness to attain some self-control and independence from parents. As youth continue to grow, they may exhibit improvements in problem-solving abilities. Hence, the youth in early adolescence may have challenges with SM as opposed to those in late adolescence (Chao et al., 2014:2). Moreover, later in adolescence, youth exhibit some reasoning and logical thinking ability. They are more able to express their feelings, speak their mind, and make complex decisions (Newman & Newman, 2012:359). The findings of this study correspond well with the literature, as SM scores were generally high, and it can be deduced that it is because most participants are older adolescents who are able to exhibit some logical reasoning and sound decision-making. The study conducted in South Africa by Kuo et al. (2019:s35) indicate that older adolescents report fewer behavioural problems compared to younger adolescents. This corresponds well with the findings of the present study because most of the participants were older adolescents with few behavioural problems.

The majority of participants in this sample were **diagnosed** with HIV at birth (60.7%; n=111) although most (99%; n=181) only learned about their status (were **disclosed to**) after the age of 12. Earlier disclosure is associated with higher SM abilities (Francis, Carryer & Wilkinson, 2019:37). The advantage of early disclosure is that the youth have enough time to deal with the external pressure of living with HIV and, thereafter, they can focus on the activities that will prolong their lives. They also experience higher levels of psychological functioning. However, in this study, older age of disclosure was associated with SM in the regression model (mean for before 12 = 84.4 vs 92.8 after 12). This is contradictory to the literature. This discrepancy may be attributed to disclosure protocols in the health facilities or cultural factors.

In this study, the total **difficulties** score had a mean of 1.26 (SD 1.7), minimum 0 and maximum 11. The strength score had a mean of 9.9 (SD 3.8), minimum 8 and maximum 10. This indicates that most participants reported several **strengths** and few difficulties. These findings correspond with the findings of a study conducted among adolescents in South Africa by Kuo et al. (2019), which indicated that higher resilience is associated with better behavioural outcomes, including less conduct problems, hyperactivity and inattention, and better peer relationships. The regression model indicated that SM improved by 0.032 units for every unit increase in individual Strengths ($p < 0.01$), but it declined by 0.074 units for each unit increase in mental health problems ($p < 0.05$). Mental health problems are prevalent amongst ALWHIV and have been associated with poor treatment outcomes (Vreeman, McCoy & Lee, 2017:101). In the present study, YLWHIV had few mental health problems, but as seen in the regression analysis, mental health problems were associated with lower SM scores.

With regards to their **health literacy**, the majority of participants (95.1%; n=174) did not have knowledge of their CD4 count, although 99.4% (n=182) reported that their viral load was undetectable. The participants with no knowledge of their CD4 counts had higher mean SM scores compared to those who knew (mean = 93.1 vs 85.1). This may be because only 9 participants reported their CD4 counts and this finding must be interpreted with caution. The association also lost significance in the regression model. According to the Lesotho ART treatment guidelines which are derived from the WHO guidelines, CD4 counts are no longer performed routinely instead viral road is recommended. (Government of Lesotho, 2016:16).

For the youth to efficiently monitor their illnesses progression and respond appropriately, they need to know the meaning of CD4 and viral load values. Knowledge of their viral load may be specifically important for youth to motivate adherence in the light of the fact that undetectable equals untransmissible (Nel, Dlamini, Meintjies, Burton, Black, Davies et al., 2020:36). It is also important for the youth to know about HIV preventative measures and to use them correctly as most of the participants indicated that they do not use condoms consistently. Consistent and correct condom use prevent them from HIV infection and reinfection, as well as prevent sexually transmitted infections from or to their partners (Mutumba et al., 2019: 4).

5.2.5.2 Family factors

Concerning **family stability**, almost two thirds of the participants (62%; n=113) had been living with the same caregiver for more than 10 years and 79.2% (n=145) had never moved in the past 5 years. The minority of participants (21.9%, n=40) had no contact with their biological mother or father. Most of the caregivers had either completed high school (36.6%; n=67) or tertiary education (36.1%; n=66). Based on these results, it can be concluded that most of the participants may have stable social support from their families as they indicated that they have resided together with the parent or caregiver for more than 10 years.

None of the family contextual factors were associated with SM. However, participants who moved 5 times or more than 5 times in the last 5 years had the lowest SM scores (means 82.5 and 87.5) versus mean scores above 92 for those who moved 3 times or less. As indicated in chapter 2, family stability and support improve SM. Family members get involved in patient care in one way or another, which promotes SM (Millard et al., 2013:24).

5.3 Limitations of the study

The researcher used a convenience-sampling technique. The researcher approached readily available participants. This is a limitation as only adherent adolescents may have been selected and the study sample had minimal variability to compare SM scores across adherent and non-adherent participants.

Only 2 facilities were included in the study, and these were facilities that provided adolescent-friendly services. These findings may, therefore, not be applicable to other settings where such services are not rendered.

Another limitation is that participants in this study may have over-estimated their own SM as this was a self-report questionnaire. This was evident in the minimal variability of the AdHIVSM scale and Strengths and Difficulties Scale (SDQ). Lastly, there was little variability in many of the contextual factor variables, for example, type of treatment regimen, adherence, general wellbeing, knowledge of treatment, etc., which precluded statistical analyses on these factors.

5.4 Conclusions

This study investigated the factors associated with SM in YLWHIV in Lesotho. The factors investigated were the condition-specific, environmental, individual, and family characteristics. Key findings from the study are that older youth constituted the majority of the participants. Most of the participants in this study were perinatally infected with HIV. Generally, adolescents had high SM scores, which corresponded well with treatment outcomes; the viral suppression rates and adherence rates were good. Although transport was reported to be an issue that sometimes prevented youth from accessing healthcare services, youth still managed to be retained in care. Some of the good practices discovered by the study are the use of youth-friendly health services that motivated youth to access services.

5.5 Recommendations

The following recommendations are based on the study’s findings and conceptual framework.

5.5.1 Youth-friendly health services

It has been observed from this study that adolescent- and youth-friendly services constitute best practices that improve the health of youth and adolescents. These kinds of services improve SM because youth become more motivated and inspired to utilise the health services. It is against this background that the researcher recommends that every hospital or clinic that has no adolescent health corner or youth-friendly services should establish them to motivate youth to access health services comfortably and conveniently (UNICEF, 2021:2).

5.5.2 Peer groups

One of the findings in the study was that participants were satisfied with the services they received at the facilities. The facilities are youth-friendly and may have led to high

SM scores among YLWHIV. However, SM scores for peer support were generally low. Therefore, there is a need to introduce peer groups all over the health facilities where youth access ART services in Lesotho so that ALWHIV can interact with peers, learn about being an adolescent and living with HIV, build skills, exchange experiences, and have fun in a secure and friendly environment (UNICEF, 2021:7).

5.5.3 Self-management education

The researcher observed most of the participants (more than half) do not know the ARVs by names. It is a recommendation that every youth who can read and understand Sesotho should know the names of the ARVs, they can also make use of technological devices such as cell phones to take the pictures of ARVs, their names and prescription chart, etc. This will assist in the cases where a youth may move to a different location as a matter of urgency or without the necessary transfer preparations. Then the youth will be able to assist with the regimen that they are taking by mentioning the names of the medication they are taking. Another observation was that participants occasionally had difficulties with transport to the health facilities. The recommendation is for outreach services to be provided, where services are provided closest to the clients (Cluver et al., 2018:9).

Other findings suggest that youth need to be assisted on improving other SM skills such as improving the communication among them and their healthcare workers, as on the question that asked whether they tell their nurses or doctors private things, the mean scores were low on the relational components. Strategies that motivate youth to communicate to their nurses and doctors need to be explored and implemented.
Findings also indicate that youth need to be empowered to practice consistent and correct use of condoms every time they practice sex, as findings indicated that they sometimes do not use condoms.

5.5.4 Future research

The researcher recommends conducting the same study with a larger population across different types of facilities. This will help researchers compare SM across types of services to establish if adolescent-friendly services affect SM. One may also need to deliberately include participants who are not doing well on treatment to make meaningful comparisons across the various contextual factors.

Qualitative studies may provide explanations for the high adherence and viral suppression rates in the present study so that recommendations can be provided for practice that can be transferred to other settings. Lastly, the AdHIVSM-35 instrument needs to be further validated in this context and with this age group. It may be needed to do further qualitative studies to ascertain which aspects of SM is relevant and valid in the context of Lesotho. There is a need for more qualitative research to explore the perceptions of YLWHIV regarding factors influencing SM.

5.6 Dissemination

Dissemination of the research will be through feedback to the Ministry of Health (MoH), Scott Hospital and the Matelile Health Centre. The research findings will be presented at various platforms and conferences both nationally and internationally. Further, an article will be published in a peer-reviewed journal.

5.7 Conclusion

The study aimed to investigate and determine the factors influencing SM in YLWHIV in Lesotho. The factors were identified. The population of the study was youth between 15-24 years, however most of the youth were between the ages of 20-24. The factors that were identified as influencing SM included the condition-specific, environmental, individual, and family factors. The study findings reveal that treatment outcomes within this population were generally good. The youth had high SM scores. The adherence as well as the viral suppression rates were good. Recommendations for future research were made.

REFERENCES

Aantjies, C.J., Ramerman, L. & Bunders, J.F.G. 2014. A systematic review of the literature on self-management interventions and discussion on their potential relevance for people living with HIV in Sub-Saharan Africa. *Patient Education and Counseling*, 95:185-200.

Adom, D., Hussein E.K. & Agyem, J.A. 2018. Theoretical and conceptual framework: Mandatory ingredients of quality research. *International Journal of Scientific Research*, 7(1):43-44.

Armstrong, A., Lorpenda, K., Caswell, G., & Kihara, C. 2017. Adolescent HIV programming: Here we come. *International HIV/AIDS Alliance, together to end AIDS 67*(1):10-42.

Avert 2020. HIV and AIDS in Lesotho. [Online] Available fromhttps://www.avert.org/professionals/hiv-around-world/sub-saharan-africa/Lesotho. [Accessed 30 November 2021]

Beachan, B.L., & Deatrick, J.A. 2014. Health Care Autonomy in Children with Chronic Conditions: Implications for Self-Care and Family Management. *PMC, 48(2):305-317.* DOI: 10.1016/j.cnur.2013.01.010

Bodenheimer, T., Wagner, E.H. and Grumbach, K., 2002. Improving primary care for patients with chronic illness: the chronic care model, Part 2. *Jama*, *288*(15):909-914.

Brashers, D.E, Neidig J.L., Reynolds, L.R. & Haas, S.M. 2017. Uncertainty in illness across the HIV/AIDS trajectory. *Journal of the Association of Nurses in AIDS Care*. 9(1):66-77.

Brink, H., Van der Walt, C. & Van Rensburg, G. 2018. *Fundamentals of research methodology for health care professionals*. 2nd ed. Cape Town: Juta & Company Ltd.

Chao, A., Whittemore, R., Minges, K.E., Murphy, K.M. & Grey, M. 2014. Self-management in early adolescence and differences by age at diagnosis and duration of type 1 diabetes. *Diabetes Educ*, 40(2):167-177.

Chenneville, T., Gabbidon, K., Lynn, C. & Rodriquez, C. 2018. Psychological factors related to resilience and vulnerability among youth with HIV in an integrated care setting. *AIDS Care*, 30:5-11. DOI: 10.1080/09540121.2018.1488032s

Chhim, K., Mburu, G., Tuot S., Sopha, R., Khol, V., Chhoun, P. & Yi, S. 2018. Factors associated with viral non-suppression among adolescents living with HIV in

Cambodia: A cross-sectional study. *AIDS Research and Therapy,* 15(1):20. DOI: org/10.1186/s12981-018-0205

Cluver, L., Pantelic, M., Toska, E., Orkin, M., Casale, M., Bungane, N. & Sherr, L., 2018. STACKing the odds for adolescent survival: health service factors associated with full retention in care and adherence amongst adolescents living with HIV in South Africa. *Journal of the International AIDS Society*, *21*(9), p.e25176.

Crowley, T. & Rohwer, A. 2021. Self-management interventions for adolescents living with HIV: A systematic review. *BMC Infectious Diseases,* 21:431. DOI: 10.1186/s12879-021-06072-0

Crowley, T. 2018. The development of an instrument to measure adolescent HIV self-management in the context of the Western Cape, South Africa. Unpublished Doctoral Dissertation. Stellenbosch: Stellenbosch University.

Crowley, T., Van der Merwe, A., Kidd, M., & Skinner, D. 2020. Adolescent human immunodeficiency virus self-management: Associations within treatment adherence, viral suppression, sexual risk behaviours and health-related quality of life. *S. Afri J HIV Med*, 21(1):a1054. DOI: 10.4102/sajhivmed.v21i1.105

Cutler, S., Crawford, P., & Engleking, R. (2018). Effectiveness of group self-management interventions for persons with chronic conditions: A systematic review. *Med/surg Nursing*, 27(6), 359–367.

Denison, J.A., Banda, H., Dennis, A.C., Packer, C., Nyambe, N., Stalter, R.M., Mwansa, J.K., Katayamoyo, P. & McCarraher, D.R. 2015. "The sky is the limit": Adhering to antiretroviral therapy and HIV self-management from the perspectives of adolescents living with HIV and their adult caregivers. *Journal of the International AIDS Society,* 18(19358):1-6.

Dlamini, S., Meintjies, G., Burton, R., Black J.M., Hefer, E., Maartens, Mangena P.M, Dow, D.E., Turner, E.I., Shayo, A.M., Mmbaga, B., Cunningham, C.K. & O'Donell, K. 2017. Evaluating mental health difficulties and associated outcomes among HIV-positive adolescents in Tanzania. *AIDS Care,* 28(7):825-833.

Elizabeth Glaser Paediatric AIDS Foundation. 2014. The Lesotho Programme. [Online]. Available from https://www.pedaids.org/wp-content/uploads/2017/11/Lesotho_us_sept-2017 [Accessed 25 September 2021]

Elizabeth Glaser Paediatric AIDS Foundation. 2017. Adolescent and Youth friendly Health services. [online] available from https://www.pedaids.org/wp-content/uploads/2018/04/Final-Draft-AYFS-Modular-training-manual.pdf [accessed 29 November 2021]

Farley, H. 2019. Promoting self-efficacy in patients with chronic disease beyond traditional education: A literature review. *Nursing open*. 7 (1):30-41 DOI: 10.1002/nop2.382

Francis, H., Carryer., & Wilkinson. 2018. Self-management support? Listening to people with complex co-morbidities. 16(3): 161-172 https://doi.org/10.1177/1742395318796176

Gage, J., Do, M. & Grant, D. 2017. Best practices for adolescent and youth-friendly HIV services. [Online]. Available from https://www.measureevaluation.org/resources/newsroom/news/best-practices-for-adolescent-friendly-youth-services.html [Accessed 15 October 2021]

Goodman, A. Lamping, D.L. & Ploubidis, G.G. 2010. When to use broader internalising and externalising subscales instead of hypothesized five subscales on the Strengths and Difficulties Questionnaire (SDQ): Data from British parents, teachers and children. *J Abnorm Child Psychol*, 38: 1179-1191.

Google maps. 2020. Available from https://www.google.com/maps/@-29.480822,28.0110942,9.07z [Accessed 20 October 2021]

Government of Lesotho. 2016. Lesotho National ART guidelines.

Government of Lesotho. 2017. Lesotho Country Report.

Government of Lesotho 2020. Social and behaviour change communication strategy for sexual and reproductive health and rights and HIV in Lesotho 2020-21 to 2022-23 [online] available from http://nac.org.ls/wp-content/uploads/2020/09/SBCC-Strategy-for-SRHR-and-HIV-in-Lesotho.pdf [accessed 29 November 2021]

Gray, R.G., Grove, S.K. & Sutherland, S. 2017. The practice of nursing research: Appraisal, synthesis, and generation of evidence. 8th edition. Elsevier Saunders, 3551 Riverport lane, St louis. Missouri

Grady P.A., & Gough L.L. 2014. Self-management: A comprehensive approach to management of chronic conditions. *Ameican journal of public health.* 104(8) 25-30

Haghitat, R.,Toska E.,Bungane, N.& Cluver L. 2021. The HIV care cascade for adolescents initiated on antiretroviral therapy in a health district of South Africa: a retrospective cohort study. *BMC Infect Dis* 21, (60): 2021

Hattingh, Dreyer & Roos. 2008. Aspects of Community Health. Oxford University press South Africa (Pty) Ltd

Help Lesotho. 2017 [online] available from https://www.helplesotho.org/lesotho/lesothohivaids-in-lesotho/ [accessed 29 November 2021]

Hoonsen, N., Davids, E.L., De Vries, P.J. & Shung-King, M. 2018. The strengths and difficulties questionnaire (SDQ) in Africa: A scoping review of its application and validation. *Child Adolesc Psychiatry Mental Health,* 12(6):1-39.

Iribarren, S., Siegel, K., Hirshfield, S., Olender, S., Voss, J., Krongold, J., Castillo, H. & Schnall, R. 2019. Self-management strategies for coping with adverse symptoms in persons living with HIV with HIV associated non-AIDS conditions. *AIDS Behav*, 22(1):297-307.

Kaunda-Khangamwa, B.N., Kapwata, P., Malisita, K. *et al.* Adolescents living with HIV, complex needs and resilience in Blantyre, Malawi. *AIDS Res Ther* **17,** 35 (2020). https://doi.org/10.1186/s12981-020-00292-1

Khalifa, A., Stover, J.B., Mahy, M.C., Idele, P., Porth, T. & Lwamba, C. 2019. Demographic change and HIV epidemic projections to 2050 for adolescents and young people aged 15-24. *Global Health Action*. 2019; 12(1) 1662685 DOI: 10.1080/16549716.2019.1662685. PMID: 31510887; PMCID: PMC6746261.

Kolawole, A.S., Shola, A.J., Oyeyemi, O.T, & Adebayo, A.S. 2014. Possible causes of premarital sex among youths as perceived by lecturers of University of Jlorin, Nigeria. *European Journal of Educational Sciences*, 1(4):1-9.

Kim, S.H., Gerver, S.M., Fildler, S. & Ward, H., 2014. Adherence to antiretroviral therapy in adolescents living with HIV: Systematic review and meta-analysis. *AIDS,* 28(13):1945-1956.

Kuo, C., LoVette, A., Pellowski, J., Harrison, A., Matthews, C., Operio, D., Beardslee, W., Stein, J.D. & Brown, L. 2019. Resilience and psychosocial outcomes among South African adolescents affected by HIV. *AIDS*, 1(33):S29-S34.

Lesotho Population-Based HIV Impact Assessment. 2017. LePHIA 2016-2017. [Online]. Available from https://phia.icap.columbia.edu/wp-content/uploads/2018/02/Lesotho-Summary-Sheet_A4.2.7.18.HR_.pdf [20.august 2021]

Lorig, K.R. & Holman, H. 2003. Self-management education: history, definition, outcomes and mechanisms. *Annuals of Behavioral Medicine,* 26(1): 1-7

Lowenthal, E.D., Bakeera-Kitaka, S., Marukutira, T., Chapman, J., Goldrath, K. & Ferrand, R. 2014. Perinatally acquired HIV infection in adolescents from sub-

Saharan Africa: A review of emerging challenges. Botswana-UPenn Scholarly Publications. 15. [Online]. Available from: http://repository.upenn.edu/botswana_schol/15 [Accessed 24 August 2019].

Low, A., Thin, K., Davia, S., Mantell, J., Koto, M., McCracken, S., Ramphalla, P., Maile, L., Ahmed, N., Patel, H. and Parekh, B., 2019. Correlates of HIV infection in adolescent girls and young women in Lesotho: results from a population-based survey. *The Lancet HIV*, *6*(9): e613-e622.

Lozano, P. & Houtrow, A. 2018. Supporting Self-management in children and adolescents with complex chronic conditions. *Pediatrics*, 141(53):S234-S241.

Mbokazi, N., Madzima, R., Leon, N., Lurie, M.N., Cornell, M., Schmidt, B.M. and Colvin, C.J., 2020. Health worker experiences of and perspectives on engaging men in HIV care: A qualitative study in Cape Town, South Africa. *Journal of the International Association of Providers of AIDS Care (JIAPAC)*, *19*: 2325958220935691.

Millard, T., Elliott, J. & Girdler, S. 2013. Self-management education programs for people living with HIV/AIDS: A systematic review. *AIDS Patient Care and STDs*, 27(2):103-113.

Modi, A.C. Pai, A.L., Hommel, K.A., Hood, K.K., Cortina, S., Hilliard, M.E, Guilfoyle, S.M., Gray, W.N. & Drotar, D. 2012. Pediatric self-management: A framework for research, practice, and policy. American *Academy of Pediatrics,* 129(2):25-155.

Mutumba, M., Mugerwa, H., Musiime, V., Gautam, A., Nakyambadde, H., Matama, C. and Stephenson, R., 2019. Perceptions of strategies and intervention approaches for HIV self-management among Ugandan adolescents: A qualitative study. *Journal of the International Association of Providers of AIDS Care (JIAPAC)*, *18*: 2325958218823246.

Navarra, A.M., Neu, N., Toussi, S., Nelson, J. and Larson, E.L., 2014. Health literacy and adherence to antiretroviral therapy among HIV-infected youth. *Journal of the Association of Nurses in AIDS Care*, *25*(3): 203-213.

Nel J, Dlamini S, Meintjes G, et al. Southern African HIV Clinicians Society guidelines for antiretroviral therapy in adults: 2020 *update. S Afr J HIV Med*. 2020; 21(1), a1115. https://doi.org/10.4102/sajhivmed.v21i1.1115

Newman, P.R. & Newman, B.M. 2012. Early adolescence and its conflict: Group identity versus alienation. *Adolescence*, 11(42):261-474.

Nöstlinger, C., Bakeera-Kitaka, S., Buyze, J., Loos, J. & Buvé, A. 2015. Factors influencing social self-disclosure among adolescents living with HIV in Eastern Africa. AIDS care, 27(Suppl 1), 36-46

Panhwar, A.H., Ansari A, D., & Sha A. 2017. Post-positivism: An effective Paradigm for social and educational research. *International research journal arts & humanities*. (45) 253-260

Pallant, J. 2016. *A step-by-step guide to data analysis using IBM SPSS*. New York, NY: 10121-2289 USA.

Pike, C., Celum, C. & Gail-Bekker, L. 2020. Adolescent healthcare: I'm lovin' it. *Southern African Journal of HIV Medicine,* 21(1):1-2.

Polit, D.F. & Beck, C.T. 2017. *Generating and assessing evidence for nursing practice*. Lippincott Williams & Wilkins.

Reynolds, N.R., Sanzero, L., Eller, P.K., Nicholas, I.B., Corless, K., Kirksey, Hamilton M.J.K., Kemppainen Bunch, K.E., Dole, P., Wantland, D., Sefcik, E. Nokes, K.M., Coleman, C.L., Canaval, M.G.E., Tsai, Y.F.2011. HIV Illness representation as a predictor of self-management and health outcome: a multi-site, cross-cultural study. *AIDS Behav .PMC* 13 (2): 258-267. DOI: 10.1007/s10461-007-9297-5

Reed, E. & Corner, J. 2015. Quality of life and experiences of care in women with metastatic breast cancer. A cross-sectional survey. *BMJ Supportive & Palliative Care*, 2015(5):358-365. DOI: 10.1136/bmjspcare-2012-000415

Ritchwood, T.D., Malo, V., Jones, C., Metzger, I.W., Atujuna, M., Marcus R., Conserve, D.F., Handler, L. & Bekker I.G. 2020. Healthcare retention and clinical outcomes among adolescents living with HIV after transition from pediatric to adult care: A systematic review. *BMC Public Health,* 20,1195 (2020). DOI: 10.1186/s12889-020-09312-1

Ruggiano, N., Shtompel, N., Whiteman. K & Sias., K. 2017. Influences of Transportation on Health Decision-Making and Self-Management Behaviors among Older Adults with Chronic Conditions. DOI: 10.1080/08964289.2015.1065788

Ryan, P. & Sawin K.J. 2009. The individual and family self-management theory: Background and perspectives on context, process and outcomes. *Nurs Outlook,* 57(4):217-225.

Sattoe, J.N.T., Bal, M.I., Roelofs, P.D., Bal R, Miedema H.S. & Van Staa, A. 2015. Self- management interventions for young people with chronic conditions: A systematic overview. *Patient Education and Counseling,* 98:704-715.

Sawin, K.J. 2017. Definitions, frameworks, and theoretical issues in self- management. Journal of Pediatrics Rehabilitation Medicine: An Interdisciplinary Approach, 10:169-176.

Schulman-Green, D., Jaser, S., Martin, F., Alonzo, A., Grey, M., McCorkle, R., Redeker, N.S., Reynolds, N. & Whittemore, R. 2012. Processes of self-management in chronic illness. *Journal of Nursing Scholarship*, 44(2):136-144.

Sharer, M. & Fullem, A. 2012. *Transitioning of care and other services for adolescents living with HIV in sub-Saharan Africa*. Arlington, VA: USAID's AIDS Support and Technical Assistance Resources.

Swedeman, D., Ingram B.L., Rotherson-Borus M. 2010. Promoting self-efficacy in patients with chronic disease beyond traditional education: A literature review. *AIDS care.* 21 (10) 1321-1334. DOI: 10.1080/09540120902803158.

UNAIDS. 2019. Global HIV & AIDS fact sheet ending the AIDS epidemic. [Online]. Available from: http://www.unids.org/en/resources/fact-sheet [Accessed 24.March 2020].

UNICEF. 2021. Adolescents HIV Prevention [Online] available from https://data.unicef.org/topic/adolescents/hiv-aids/#:~:text=HIV%20in%20adolescents,of%20new%20adult%20HIV%20infections . [Accessed 29 November 2021]

Vasuthevan, S., & Mthembu S. 2014. De Haan's Health of Southern Africa. Juta & company. Cape Town South Africa

Vreeman, R. C., McCoy, B. M., & Lee, S. 2017. Mental health challenges among adolescents living with HIV. Journal of the International AIDS Society, 20(Suppl 3) 21497. https://doi.org/10.7448/IAS.20.4.21497 1758-2652

World Health Organization. 2010. Participant manual: IMAI one-day orientation on adolescents living with HIV. WHO Press, World Health Organization, Geneva, Switzerland. ISBN 978 92 4 159897 2

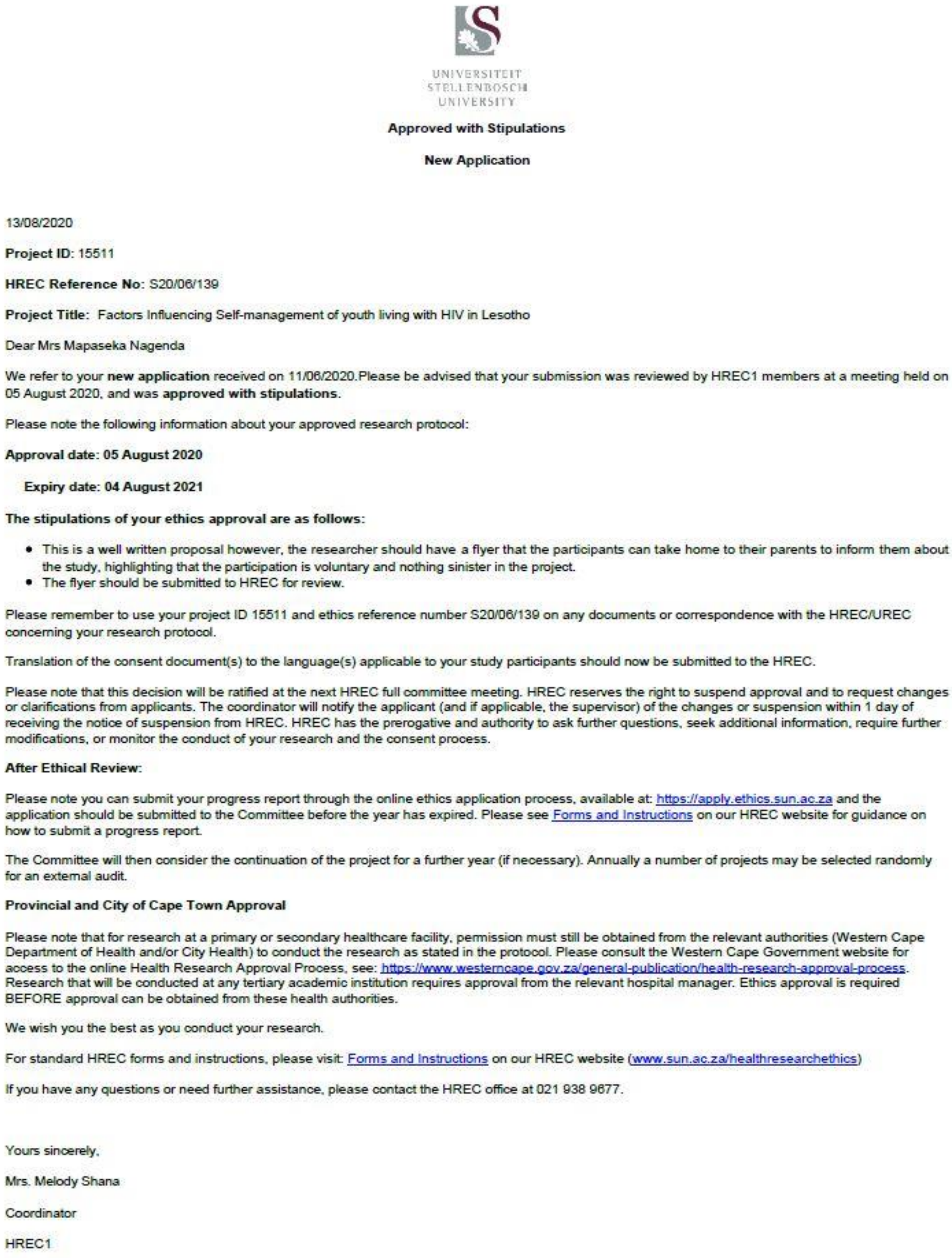
World Health Organisation. 2014. Health for the world's adolescents: A second chance in the second decade. [Online]. Available from: http://apps.who.int/iris/bitstream/10665/112750/1/WHO_FWC_MCA_14.05_eng.pdf?ua=1 [Accessed 24 August 2019].

World Health Organisation. 2021. Updated recommendations on HIV prevention, infant diagnosis, antiretroviral initiation and monitoring: March 2021. [online]

available from file:///C:/Users/User/Downloads/9789240022232-eng.pdf [accessed 29 November 2021]

Xu, L. Munir, K, Kanabkaew C., Le Coeur., S. 2017. Factors influencing antiretroviral treatment suboptimal adherence among perinatally HIV-infected adolescents in Thailand. *PLoS One.* 12(2) e 0172392. DOI: 10.1371/journal.pone.0172392. PMID: 28207891; PMCID: PMC5312953.

Appendix 1: Ethical approval from Stellenbosch University



UNIVERSITEIT
STELLENBOSCH
UNIVERSITY

Approved with Stipulations

New Application

13/08/2020

Project ID: 15511

HREC Reference No: S20/06/139

Project Title: Factors Influencing Self-management of youth living with HIV in Lesotho

Dear Mrs Mapaseka Nagenda

We refer to your **new application** received on 11/06/2020.Please be advised that your submission was reviewed by HREC1 members at a meeting held on 05 August 2020, and was **approved with stipulations**.

Please note the following information about your approved research protocol:

Approval date: 05 August 2020

Expiry date: 04 August 2021

The stipulations of your ethics approval are as follows:

- This is a well written proposal however, the researcher should have a flyer that the participants can take home to their parents to inform them about the study, highlighting that the participation is voluntary and nothing sinister in the project.
- The flyer should be submitted to HREC for review.

Please remember to use your project ID 15511 and ethics reference number S20/06/139 on any documents or correspondence with the HREC/UREC concerning your research protocol.

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

Please note that this decision will be ratified at the next HREC full committee meeting. HREC reserves the right to suspend approval and to request changes or clarifications from applicants. The coordinator will notify the applicant (and if applicable, the supervisor) of the changes or suspension within 1 day of receiving the notice of suspension from HREC. 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:

Please note you can submit your progress report through the online ethics application process, available at: https://apply.ethics.sun.ac.za and the application should be submitted to the Committee before the year has expired. Please see Forms and Instructions on our HREC website for guidance on how to submit a progress report.

The Committee 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.

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 (www.sun.ac.za/healthresearchethics)

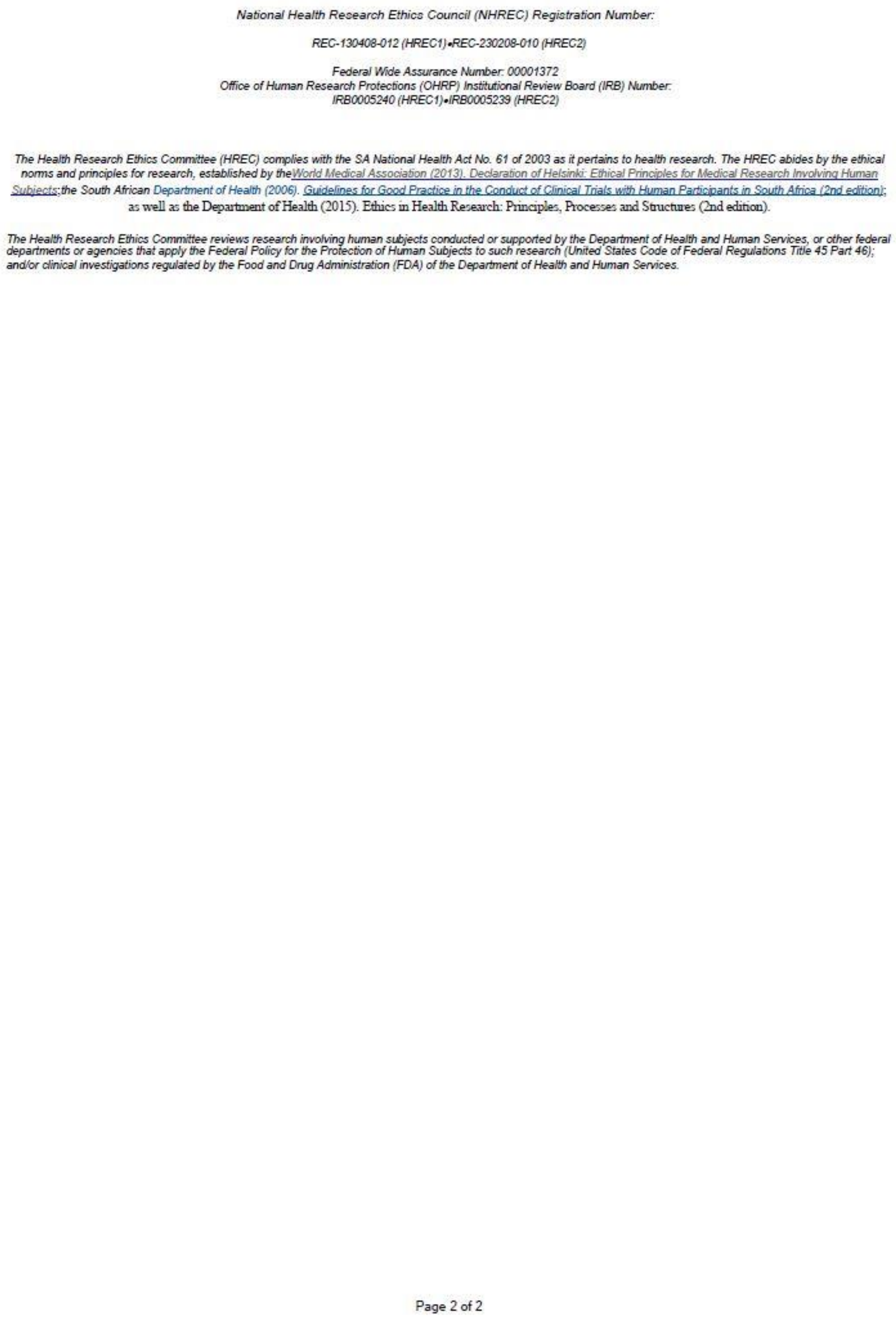
If you have any questions or need further assistance, please contact the HREC office at 021 938 9677.

Yours sincerely,

Mrs. Melody Shana

Coordinator

HREC1



National Health Research Ethics Council (NHREC) Registration Number:

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

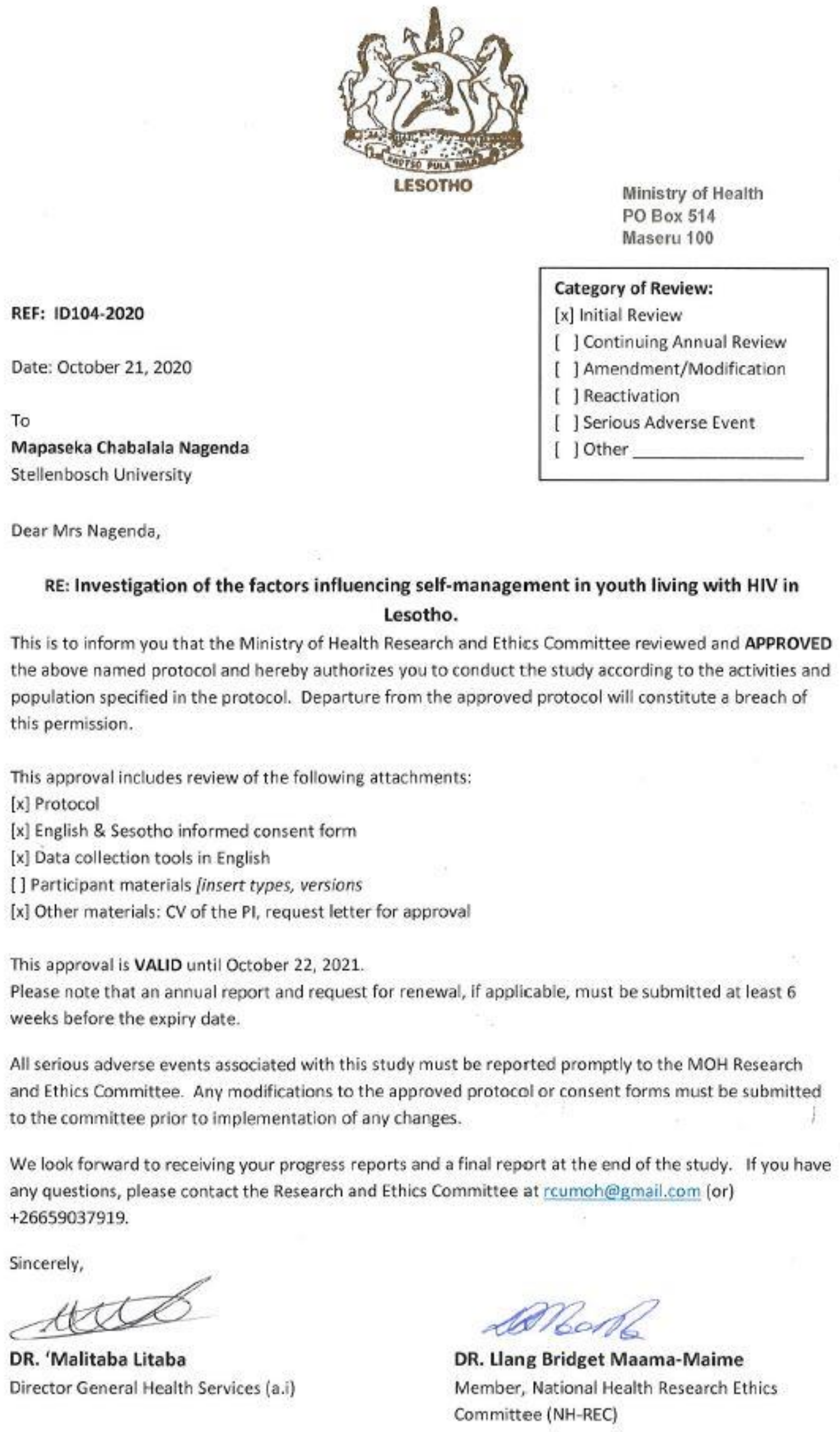
Federal Wide Assurance Number: 00001372
Office of Human Research Protections (OHRP) Institutional Review Board (IRB) Number:
IRB0005240 (HREC1)•IRB0005239 (HREC2)

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.

Page 2 of 2

Appendix 2: Permission obtained from the Ministry of Health, Lesotho



LESOTHO

Ministry of Health
PO Box 514
Maseru 100

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

REF: ID104-2020

Date: October 21, 2020

To
Mapaseka Chabalala Nagenda
Stellenbosch University

Dear Mrs Nagenda,

RE: Investigation of the factors influencing self-management in youth living with HIV in Lesotho.

This is to inform you that the Ministry of Health Research and Ethics Committee reviewed and **APPROVED** the above named protocol and hereby authorizes you to conduct 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
[x] English & Sesotho informed consent form
[x] Data collection tools in English
[ ] Participant materials *[insert types, versions*
[x] Other materials: CV of the PI, request letter for approval

This approval is **VALID** until October 22, 2021.
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) +26659037919.

Sincerely,

DR. 'Malitaba Litaba
Director General Health Services (a.i)

DR. Llang Bridget Maama-Maime
Member, National Health Research Ethics Committee (NH-REC)

Appendix 3: Participant and parent information leaflet and declaration of consent by participant and investigator

Title of Research Project:	
FACTORS INFLUENCING THE SELF MANAGEMENT OF YOUTH LIVING WITH HIV IN LESOTHO	
DETAILS OF PRINCIPAL INVESTIGATOR (PI):	
Title, first name, surname: Mapaseka Chabalala Nagenda	Ethics reference number:
Full postal address: PO.BOX 10614 MASERU 100	PI Contact number: +266 58739899

We would like to invite you 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 or field worker any questions about any part of this project that you do not fully understand. It is very important that you are completely satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. In other words, you may choose to take part, or you may choose not to take part. Nothing bad will come of it if you say no: it will not affect you negatively in any way whatsoever. Refusal to participate will involve no penalty or loss of benefits or reduction in the level of care to which you are otherwise entitled to. You are also free to withdraw from the study at any point, even if you do agree to take part initially.

This study has been approved by the Health Research Ethics Committee at Stellenbosch University. The study will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, the South African Guidelines for Good Clinical Practice (2006), the Medical Research Council (MRC) Ethical Guidelines for Research (2002), and the Department of Health Ethics in Health Research: Principles, Processes and Studies (2015).

What is this research study all about?

The research is about investigating the factors influencing self-management in youth living with HIV in Lesotho. Self-management means the things that you have to do daily to take care of your health. Factors that can influence self-management may include things related to yourself, your family, or your environment.

Where will the study be conducted?

The study will be conducted at Scott hospital adolescent health corner and Matelile clinic, which one of the clinics under the supervision of the Scott hospital.

The number of participants from Scott hospital will be 94, while the participants from Matelile health centre will be 90. The total number of the participants is 184.

Why do we invite you to participate?

We invite you to participate because you are a youth between the ages of 15-24 years who is living with HIV and you are drinking anti-retroviral therapy (ARVs) for your health.

What will your responsibilities be?

Your responsibility is to provide information that is required from you, by filling in the questionnaire that will be provided to you to the best of your ability. When you come for your clinic follow up, you will be given a consent form that explains the study and the aims, and then if you agree to take part, you will be given a questionnaire to complete. You are welcome to ask questions if there is anything you do not understand. The time needed for you to fill in the form might be approximately 30 minutes. You will be requested to complete the questionnaire only once.

Will you benefit from taking part in this research?

The study will not have any direct benefits to you as the participant. The study may benefit other youth living with HIV as we will make recommendations on how youth living with HIV can be assisted to better take care of themselves.

Are there any risks involved in your taking part in this research?

The possible anticipated risk is you feeling uncomfortable or emotional due to the questions that you have to answer by filling in the questionnaire. If you feel uncomfortable or emotional, please inform the researcher or field worker. You do not have to answer any questions you do not feel comfortable to answer. You may also

spend more time than you usually do at the facility because you have to fill in the questionnaire.
The researcher is going to provide some snacks so that in case you become hungry you will have a snack to eat.

Who will have access to your medical records?
Any information you share with me during this study and that could possibly identify you as a participant will be protected. Your treatment regimen (the names of your ARVs) and your viral load (blood results) will be accessed from your clinic records. The questionnaire that you fill in will not have your name on it. The consent form and questionnaires will be stored separately in lockable lockers, in offices with only limited access to the researcher. At the time when you are completing a questionnaire, you will be alone in a room which will be given to you as well as the fieldworker. Your name and the name of this clinic will not be identified by names in the research reports.

During publication of the study results, confidentiality and anonymity will still be maintained, meaning that no names of persons or organisations will be mentioned.

Will you be paid to take part in this study and are there any costs involved?
It will not cost you anything to take part in this study. You will not be paid for participating in this study, however, you will be provided with snacks as your anticipated time of stay at the facility may be longer than usual.

Declaration by participant
By signing below, I …………………………………..…………. agree to take part in a research study entitled (Factors influencing Self-management in youth living with HIV in Lesotho).
I declare that:

- I have read this information and consent form, or it was read to me, and it is written in a language in which I am fluent and with which I am comfortable.
- I have had a chance to ask questions and I am satisfied that all my questions have been 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 nothing bad will come of it – I will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan that we have agreed on.
- I give the researcher permission to obtain the names of my ARV's and my blood results (viral load) from my clinic folder.

Signed at (*place*) ....….......…………….. On (*date*) …………...……….. 2020.

Signature of participant ………………… Signature of witness …………………..

Declaration by investigator

I Mapaseka Chabalala Nagenda…………………………………………..……… declare that:

I explained the information in this document in a simple and clear manner to …………………………………..

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

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

Signed at (*place*) ....….......…………….. On (*date*) …………...……….. 2020.

Signature of investigator……………………. Signature of witness ……………………….

PARENT/GUARDIAN INFORMATION LEAFLET

TITLE OF RESEARCH PROJECT:	
FACTORS INFLUENCING THE SELF MANAGEMENT OF YOUTH LIVING WITH HIV IN LESOTHO	
DETAILS OF PRINCIPAL INVESTIGATOR (PI):	
Title, first name, surname: Mapaseka Chabalala Nagenda	**Ethics reference number:**
Full postal address: PO.BOX 10614 MASERU 100	**PI Contact number: +266 58739899**

Dear parent/guardian**,** I am a student at Stellenbosch University doing second year of Masters in Nursing. I am conducting a study about the topic below:
Investigating the factors influencing self-management in youth living with HIV in Lesotho. Self-management means the things that one has to do daily to take care of their health. Factors that can influence self-management may include things related to oneself, your family, or your environment.

Your child has been asked to participate in this study because he/she is living with HIV and taking anti-retroviral treatment. Participating in the study involves completing a questionnaire of about 30 minutes. This will be done at the clinic during the time your child is accessing routine health care. Since your child accesses services on his/her own, I have explained the study to your child and he/she provided their assent to participate. Your child received a copy of this assent document to take home.

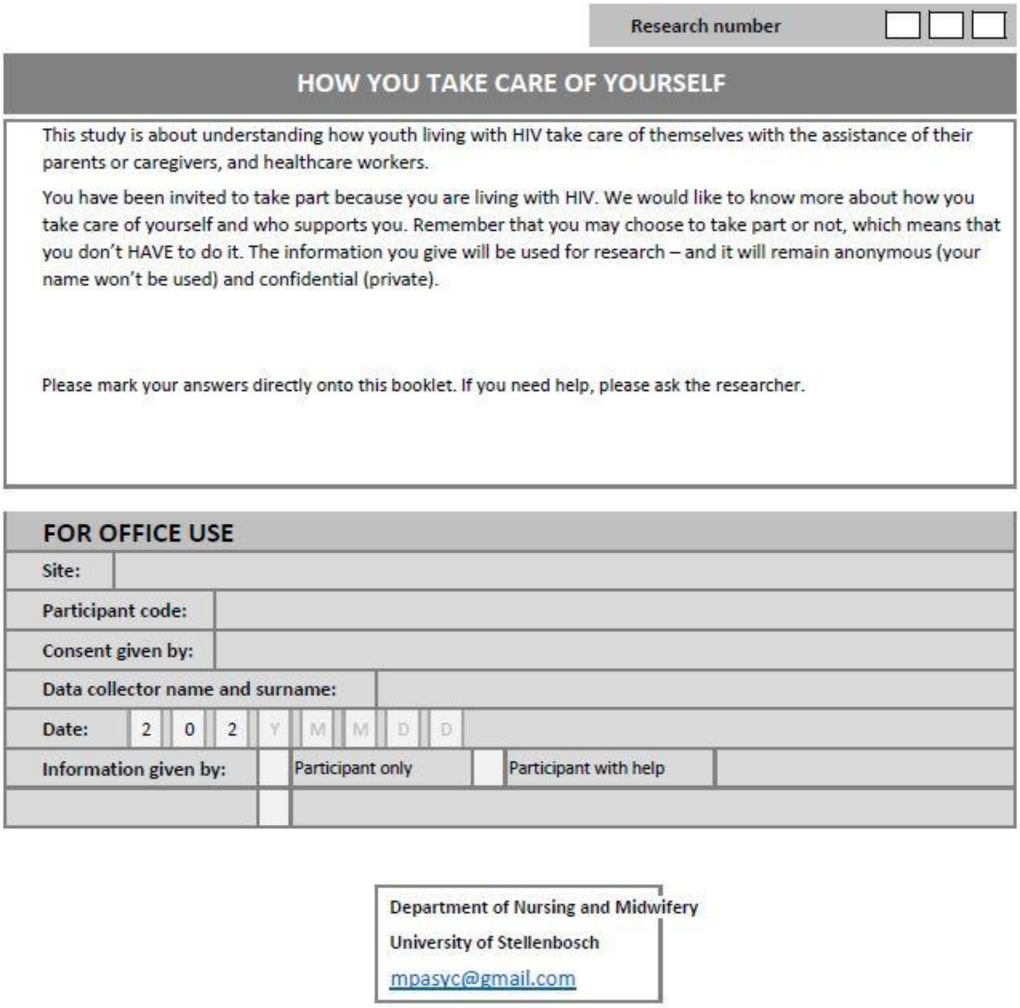
The study is voluntary, your child will not be denied services for not taking part in the study. Your child will not be paid for participating in this study, neither will she/he benefit directly, but the study will assist in informing future decisions about health care services. If you have questions and concerns, please do not hesitate to contact the Primary Investigator.

Mapaseka Chabalala Nagenda

……………………………………………..

Number: 58739899

Appendix 4: Data collection instrument



Research number ☐☐☐

HOW YOU TAKE CARE OF YOURSELF

This study is about understanding how youth living with HIV take care of themselves with the assistance of their parents or caregivers, and healthcare workers.

You have been invited to take part because you are living with HIV. We would like to know more about how you take care of yourself and who supports you. Remember that you may choose to take part or not, which means that you don't HAVE to do it. The information you give will be used for research – and it will remain anonymous (your name won't be used) and confidential (private).

Please mark your answers directly onto this booklet. If you need help, please ask the researcher.

FOR OFFICE USE

Site:	
Participant code:	
Consent given by:	
Data collector name and surname:	
Date:	2 0 2 Y M M D D
Information given by:	☐ Participant only ☐ Participant with help
	☐

Department of Nursing and Midwifery
University of Stellenbosch
mpasyc@gmail.com

1 BACKGROUND INFORMATION

Please tell us a bit more about yourself. If there is more than one option at a question, choose the best one, and only mark one answer.

QUESTIONS ABOUT YOU

1 **Date of birth** Y Y Y Y M M D D

2 **Home language** ☐ Sesotho ☐ English Other ____________

3 **Are you currently in school?** ☐ Yes ☐ No

4 **What is the highest grade that you have completed?**

☐ Std 5 ☐ std 6 ☐ std 7 ☐ Form A ☐ Form B

☐ Form C ☐ Form D ☐ Form E

5 **I see myself as:** ☐ Male ☐ Female ☐ I choose not to say

☐ Transgender

6 **My ID document says that I am:** ☐ Male ☐ Female ☐ I choose not to say

QUESTIONS ABOUT YOUR FAMILY

7 **With whom do you stay? That will be your primary caregiver or the person who looks after you.**

☐ Biological mother ☐ Family member (aunt, grandmother, sister, brother, etc.)

☐ Biological father ☐ Adoptive parents

☐ Biological father and mother ☐ Other ____________

8 **How long have you lived with the person who looks after you?**

☐ Less than one year ☐ 1-5 years ☐ 6-10 years ☐ More than 10 years

9 **What is the level of education of the person who looks after you?**

☐ No formal schooling ☐ Primary school ☐ High school

☐ College or university ☐ Not sure/don't know

10 **How many people live in the same house as you? (Include yourself when you count)** __

11 **How many times have you moved house in the past 5 years? (Please tick the correct number)**

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ More than 5.

12 **Is your biological mother still alive?** ☐ Yes ☐ No ☐ Not sure

13 **Is your biological father still alive?** ☐ Yes ☐ No ☐ Not sure

14 **Are you still in touch with your biological mother or father?**

☐ Yes, with my mother and my father ☐ Yes, only with my mother ☐ Yes, only with my father

☐ No

QUESTIONS ABOUT YOUR HEALTH

15 **When were you diagnosed with HIV?**

☐ At birth ☐ Before the age of 6 ☐ Between 6 and 12

☐ After the age of 12 ☐ I don't know

16 **At what age did you find out that you are HIV positive?**

☐ Between the ages of 6 and 10 ☐ After the age of 12

☐ Between the ages of 10 and 12

17 **What is your most recent CD4 cell count?** ____________ (Write it down if you know it)

☐ Don't know/not sure

18 Write down what you understand about a CD4 count:

____

19 What is your most recent viral load? ________ (Write it down if you know it)

☐ Undetectable
☐ Don't know/not sure

20 Write down what you understand about a viral load:

____

19 Do you have any other health conditions or illnesses at the moment?

☐ Yes ☐ No ☐ I don't know

21 Please mark the illnesses that you have, or write them down if they are not on this list:

☐ High blood pressure ☐ Malaria ☐ Hepatitis ☐ TB
☐ Depression ☐ Diabetes ☐ ADHD

Other ________________________________

____

22 How did you become infected with HIV? Please circle 'Yes' or 'No' for each line.

At birth/from my mother (mother-to-child transmission)	Yes	No
By having sex	Yes	No
Forced sex or abuse	Yes	No
Shared needles or recreational drug equipment	Yes	No
Blood transfusion or other medical procedure	Yes	No
I don't know/I'm not sure	Yes	No

23 How would you rate your own health?

☐ Very healthy ☐ Healthy ☐ Not so healthy ☐ Not healthy at all

The following questions concerns your mental health
During the past 12 months have you felt the following for 2 weeks in a row?

24	Sad, angry, or depressed	Yes	No
25	That you lost interest in most things that usually give you pleasure	Yes	No
26	Worried or anxious most of the time	Yes	No

2 YOUR TREATMENT

1 **Which of these three choices describes you best? Choose one.**

☐ I have never taken ARVs (**please skip all the questions in this section and go to section 4**).

☐ I am taking ARVs at the moment (**please go on to question 2**).

☐ I started taking ARVs but I've stopped taking it (**please skip questions 2-8 and continue from question 9 of this section**).

2 **How long have you been taking HIV medication (ARVs)? Choose one.**

☐ Less than one year ☐ 1-5 years ☐ 6-10 years

☐ More than 10 years ☐ Don't know/Not sure

HOW ARE YOU TAKING YOUR ARVs?

3 **How many tablets do you take every day? Choose one.**

☐ 1 ☐ 2 ☐ 3 ☐ More than 3 ☐ Don't know/not sure

4 **How often do you have to take your tablets? Choose one.**

☐ Once a day (for example, evening only)

☐ Two times a day (for example, morning and evening)

☐ More than two times a day (for example, morning, lunch and evening)

☐ Don't know/Not sure

5 **In general, over the <u>PAST MONTH</u>, how often did you miss taking your ARVs?**

☐ I hardly ever take any of my ARVs

☐ I miss most of my ARVs

☐ I miss about half of my ARVs

☐ I miss my ARVs a little bit of the time

☐ I never miss any of my ARVs

6 **How many times did you miss taking your ARVs over the <u>LAST WEEK</u>?**

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

Complete this section <u>ONLY</u> if you started taking ARVs but then stopped taking them.

8 **What month and year did you STOP taking your ARVs?**

☐☐/☐☐

(month) (year)

☐ Don't know/not sure

How did you decide to stop taking your ARV medications?

☐ I decided to stop by myself.

☐ The doctor/nurse recommended that I should stop.

☐ The doctor/nurse and I decided together that I should stop.

9 **People stop taking their medication for various reasons. Please choose all the reasons why you stopped taking your HIV medication.**

☐ Side-effects. Please write them down: ____________________

☐ My ARVs weren't working.

☐ I became tired of taking the tablets.

☐ It was too hard to take the tablets every day.

☐ Other reasons. Please write them down: ____________________

3 YOUR CLINIC OR HOSPITAL

Please choose one option for each question about the clinic or hospital you go to for your HIV care:

1 The staff at the clinic have time for me.

☐ Always ☐ Usually ☐ Sometimes ☐ Never

2 The staff treats me with respect.

☐ Always ☐ Usually ☐ Sometimes ☐ Never

3 In general, how satisfied are you with the service you receive at the clinic or hospital?

☐ Very satisfied ☐ Satisfied ☐ Dissatisfied ☐ Very dissatisfied

4 Do you like going to the clinic or hospital?

☐ Yes ☐ No

5 Do you think this clinic or hospital meet the needs of adolescents and young people?

☐ Yes ☐ No

6 Do transport problems prevent you from going to the clinic or hospital?

☐ Always ☐ Usually ☐ Sometimes ☐ Never

4 TAKING CARE OF YOURSELF

We would like to know how you take care of yourself. Think about your thoughts, feelings and actions over the PAST MONTH when you answer these questions.

Please answer all the questions below by marking one answer for each statement.		Strongly agree	Agree	Disagree	Strongly disagree
1	I know the signs and symptoms of my illness (HIV) (for example, when I am sick or have side-effects from my ARVs).				
2	I can get information about HIV.				
3	I know the date of my next hospital or clinic appointment.				
4	I know how to contact the doctor or nurse if I need to.				
5	I can achieve as much as other people who don't have HIV.				
6	My faith helps me to stay positive about myself and my future.				
7	I am confident I can take care of my health.				
8	I would cope if I told someone about my HIV status and that person didn't accept it or ignored me.				
9	I would tell my parents or teacher if I were being bullied (physically or verbally) and it felt out of my control.				
10	I decide by myself whom I want to tell about my HIV status.				

		Always	Most of the time	Some-times	Never
11	I can cope with it if people say nasty or hurtful things about people living with HIV.				
12	Doing things I like (for example, listening to music, reading or playing sport) helps me to cope.				
13	Things like eating junk food, smoking cigarettes, drinking alcohol or taking drugs help me to cope.				
14	I aim to be independent (taking care of myself).				
15	I aim to enjoy life, feel good and have fun.				
16	I aim to be successful (for example, finishing school, studying further or getting a job).				
17	I feel confident I can meet my health and life goals.				
18	I do things to improve my health (for example, by exercising or eating healthy foods).				
19	I attend clinic appointments on my own.				
20	I attend clinic appointments on scheduled dates (for example, I use a calendar, phone or my clinic card to remind myself).				
21	I take part in decisions about my health and treatment (for example, I tell the doctor or nurse what I think and we make decisions together).				
22	I ask the doctor or nurse questions when there is anything I don't understand.				
23	I tell the doctor or nurse how I am feeling (for example, when I feel sick, depressed or have side-effects because of my treatment).				
24	I tell the doctor or nurse when I miss a dose of my ARVs.				
25	I tell the doctor or nurse about private things (for example, if I am having sex or using drugs or alcohol).				
26	My family supports me to live with HIV.				
27	The doctors, nurses and counsellors at the clinic support me to live with HIV.				
28	Other adolescents at the clinic (for example, in my support group or club) support me to live with HIV.				
29	I have regular contact with friends (for example, at school or in my community).				
30	I participate in activities at school or in my community.				
31	I would find help in my community if I needed it (for example, a social worker if I had problems at home or at school).				

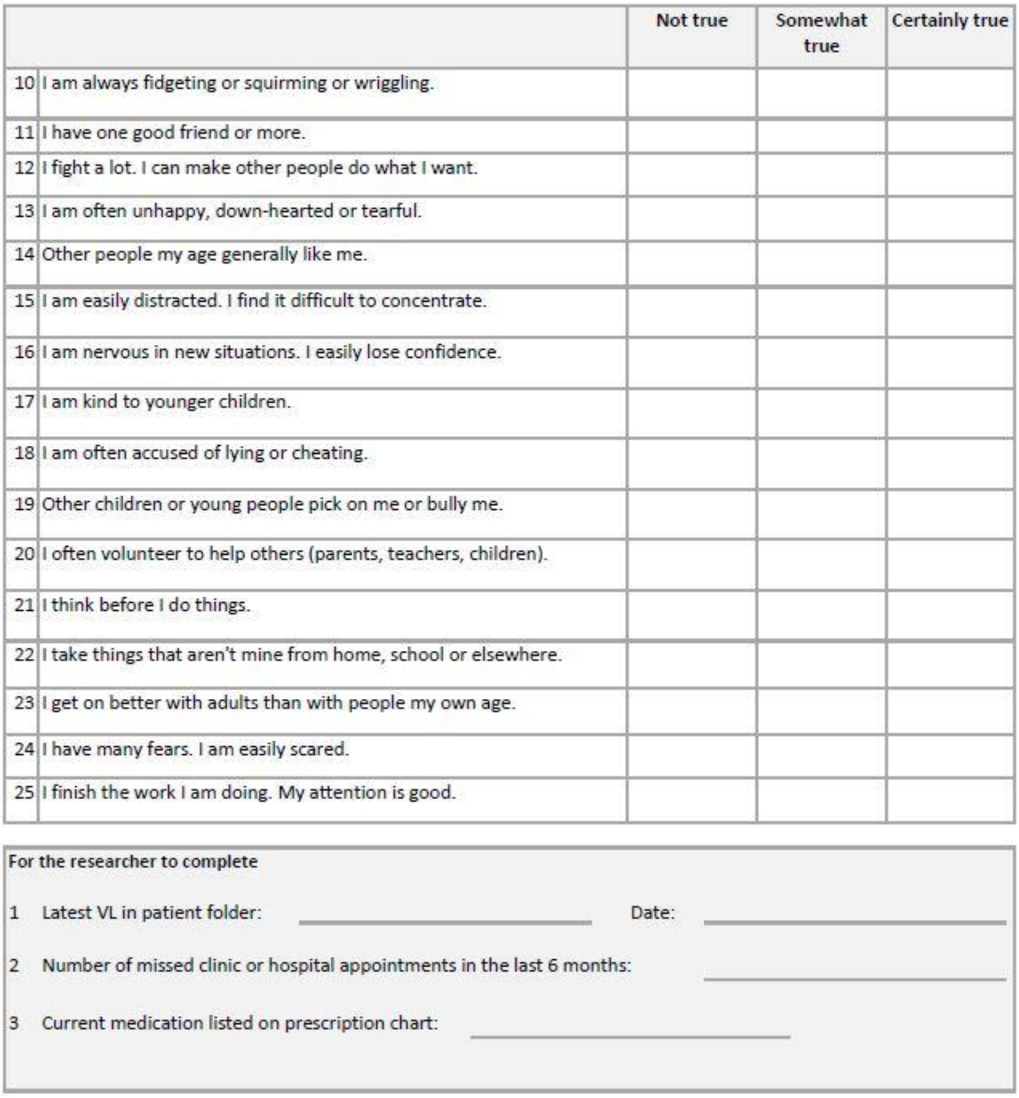
	Answer question 32-43 if you take ARVs. If you do not take ARVs, go to question 44.	Strongly agree	Agree	Disagree	Strongly disagree
32	I understand why I am taking ARVs.				
33	I know the names of the ARVs.				
34	I know at what times I should take my ARVs.				
35	I know what to do when I miss the time to take my ARVs.				
36	I understand what will happen if I don't take my ARVs every day.				
37	I know what my viral load is.				
38	I know what my viral load should be.				
		Always	Most of the time	Some-times	Never
39	I rely on other people to remind me to take my ARVs				
40	Other things interfere with my plans to take ARVs (for example, when I go to a party or sleepover or when I do drugs).				
41	Don't remember/not sure if tablets were taken.				
42	I aim to understand why my viral load is high or low.				
43	I take my ARVs even when I don't want to (for example, when I feel depressed or am tired of taking them).				
	Answer question 44 if you are having sex. If you are not having sex,	Always	Most of	Some-	Never
44	My partner and I use a condom when we have sex.				

5 YOUR STRENGTHS AND DIFFICULTIES YOU HAVE

Please answer as best you can, even if you're not absolutely sure.

Think back and give your answer based on your behaviour over the LAST 6 MONTHS. Choose one option for each question.

		Not true	Somewhat true	Certainly true
1	I try to be nice to other people. I care about their feelings.			
2	I'm restless, I can't stay still for long.			
3	I get a lot of headaches, stomach aches or other sicknesses.			
4	I usually share with others (food, games, pens, etc).			
5	I get very angry and often lose my temper.			
6	I am usually on my own. I usually play alone or keep to myself.			
7	I usuallly do as I'm told.			
8	I worry a lot.			
9	I am helpful when someone is hurt, upset, or feeling ill.			



		Not true	Somewhat true	Certainly true
10	I am always fidgeting or squirming or wriggling.			
11	I have one good friend or more.			
12	I fight a lot. I can make other people do what I want.			
13	I am often unhappy, down-hearted or tearful.			
14	Other people my age generally like me.			
15	I am easily distracted. I find it difficult to concentrate.			
16	I am nervous in new situations. I easily lose confidence.			
17	I am kind to younger children.			
18	I am often accused of lying or cheating.			
19	Other children or young people pick on me or bully me.			
20	I often volunteer to help others (parents, teachers, children).			
21	I think before I do things.			
22	I take things that aren't mine from home, school or elsewhere.			
23	I get on better with adults than with people my own age.			
24	I have many fears. I am easily scared.			
25	I finish the work I am doing. My attention is good.			

For the researcher to complete

1 Latest VL in patient folder: ______________ Date: ______________

2 Number of missed clinic or hospital appointments in the last 6 months: ______________

3 Current medication listed on prescription chart: ______________

Appendix 5: Declaration by language editor

DECLARATION BY EDITOR

Stellenbosch

29 November 2021

To whom it may concern

RE: Editing of thesis

This letter serves as confirmation that I, Selene Delport, edited the master's thesis of Mapaseka Chabalala. Changes were indicated in track changes and comment boxes. Implementation of these changes was left up to the author.

Sincerely,

Selene Delport

Freelance editor

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Appendix 6: Declaration of translation

NOMA LANGUAGE TRANSLATION SERVICES

DECLARATION OF THE QUESTIONNAIRE TRANSLATION PROCESS:

I_Nomaswati Lestolo here with the below description, verify the translation process of the data collection tool.

The questionnaire was translated to Sesotho. The translation process included a forward translation of the questionnaire , with my expertise in Sesotho language I translated the English version of the questionnaire to Sesotho and handed it over to colleague who is also conversant with languages to check the translation and compare it with the English version of the questionnaire. Discrepancies were rectified and resolved before the questionnaires was used.

For question and queries, please contact me.

Yours sincerely

Nomaswati Lets'olo

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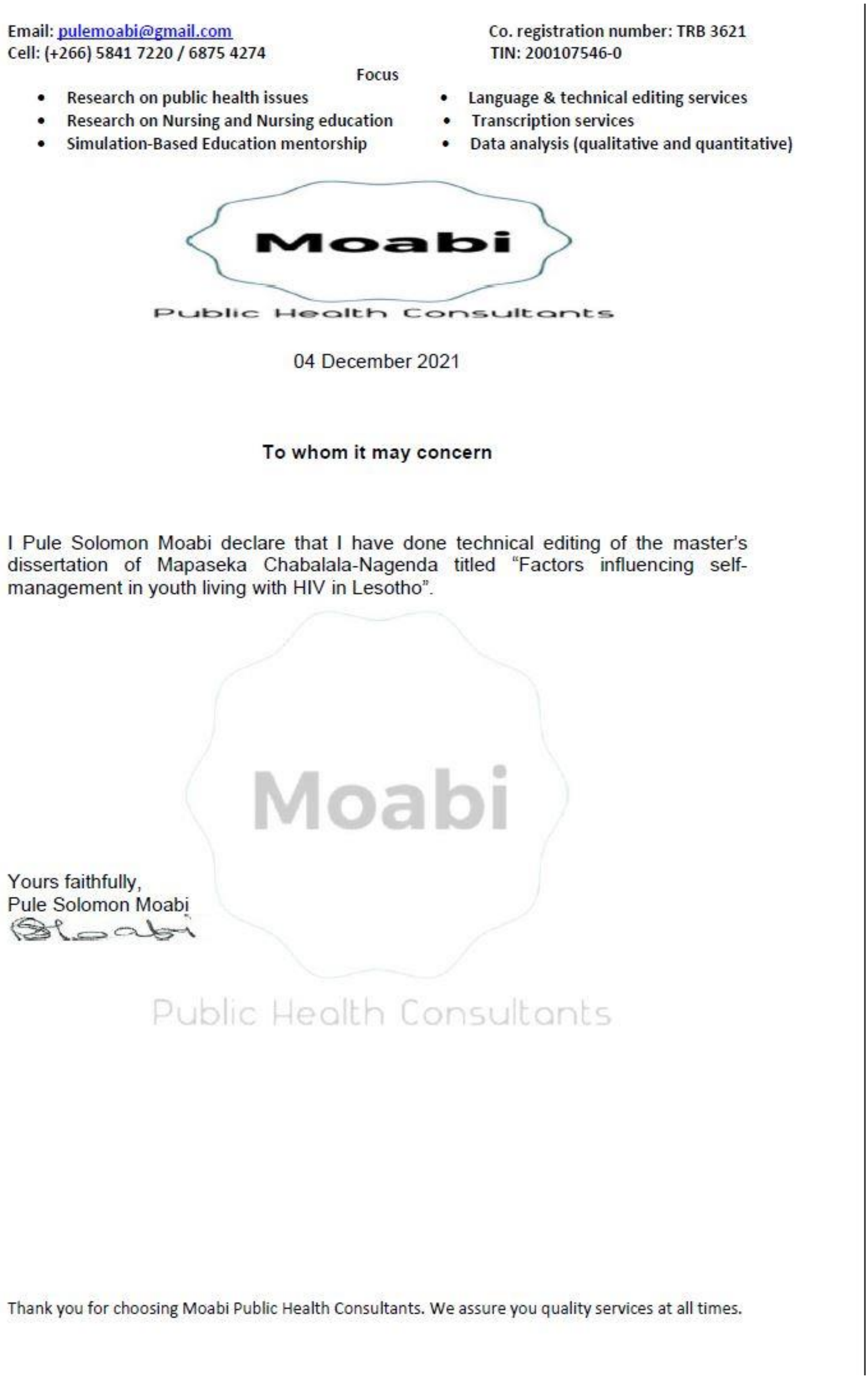
Appendix 7: Declaration by technical editor



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Focus

- Research on public health issues
- Research on Nursing and Nursing education
- Simulation-Based Education mentorship
- Language & technical editing services
- Transcription services
- Data analysis (qualitative and quantitative)

Moabi
Public Health Consultants

04 December 2021

To whom it may concern

I Pule Solomon Moabi declare that I have done technical editing of the master's dissertation of Mapaseka Chabalala-Nagenda titled "Factors influencing self-management in youth living with HIV in Lesotho".

Yours faithfully,
Pule Solomon Moabi

Thank you for choosing Moabi Public Health Consultants. We assure you quality services at all times.