

AMERICAN UNIVERSITY OF BEIRUT

EXPLORING HIV HEALTHCARE SERVICE ACCESS  
ISSUES EXPERIENCED BY ADOLESCENTS LIVING WITH  
HUMAN IMMUNODEFICIENCY VIRUS (HIV) IN AN HIV-  
DESIGNATED HEALTHCARE CENTER IN ESWATINI

by  
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A thesis  
submitted in partial fulfillment of the requirements  
for the degree of Master of Science in Nursing  
to the Rafic Hariri School of Nursing  
at the American University of Beirut

Beirut, Lebanon  
January 2024

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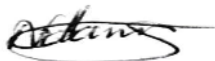
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## ACKNOWLEDGEMENTS

This work would not have been possible without the unwavering and holistic financial support, mentorship, and fervent encouragement from the Mastercard Foundation Scholars Program at the American University of Beirut. I am utterly grateful for your heartfelt guidance!

I would also like to acknowledge and give my warmest thanks to my Thesis Supervisor and Thesis Committee Chairperson Dr. Gladys Honein-AbouHaidar who made this work possible. Her guidance and advice carried me through all the stages of writing my thesis. I would also like to unreservedly thank my thesis committee members: Dr. Jocelyn DeJong and Dr. Marina Gharibian Adra for letting my defense be an enjoyable moment, and for your brilliant comments and suggestions, thanks to you. I am utterly grateful for the abundant support and reflective feedback!

To the amazing staff and Faculty Members at the American University of Beirut, thank you for guiding, teaching, and providing all the support I needed to complete this milestone.

To all the numerous friends, family, and well-wishers who offered kindness, love, and company on this journey I am truly grateful.

I would like to extend my sincere thanks to all of the participants in my study, who generously shared their time, experiences, and insights with me. Their willingness to engage with our research was essential to the success of the thesis, and I am deeply grateful for their participation.

Finally, I would like to thank God, for letting me through all the challenges. I have experienced your guidance. I shall keep on trusting you for my future.

# ABSTRACT

## OF THE THESIS OF

Celumusa Cleanboy Ndlangamandla for Master of Science in Nursing  
Major: Community and Public  
Health Nursing

Title: Exploring HIV Healthcare Service Access Issues Experienced by Adolescents Living with Human Immunodeficiency Virus (Hiv) in an HIV-Designated Healthcare Center in Eswatini

**Background:** HIV remains the leading cause of death among adolescents in Eswatini. The prevalence of HIV among adolescents is increasing as is the number of adolescents living with HIV who experience HIV service access issues. In Eswatini, previous studies explored general experiences of ALHIV with a limited focus on access to HIV healthcare services. The study aimed to describe access issues to HIV healthcare services among adolescents living with HIV in an HIV-designated healthcare center in Eswatini, while exploring the factors influencing HIV service access and suboptimal compliance to HIV treatment.

**Methodology:** The study used an exploratory-descriptive qualitative design. Adolescents were sampled using purposive sampling and healthcare providers were sampled through convenience sampling.

**Results:** Adolescents face challenges that limit their ability to perceive a need for HIV care, seek HIV care, reach HIV care, pay for HIV, and engage in HIV care. This is despite some efforts made by the health system through its five dimensions of healthcare access as outlined in the Levesque conceptual framework to facilitate their visibility and success in enhancing adolescents' abilities.

**Discussion:** Both the health system factors, and HIV service beneficiaries influence the accessibility of HIV services. A unified effort is needed to address the HIV service access issues experienced by adolescents living with HIV if the country is to achieve local and global HIV targets by 2030.

**Conclusion:** Adolescents living with HIV are a uniquely vulnerable population facing challenges around accessing HIV services and engaging in sustained HIV care. Promoting access to HIV services for the most vulnerable adolescents will require interventions that address both social and health system factors. The findings have implications for programs that will empower both the health system and adolescents living with HIV.

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## ABBREVIATIONS

AGYW	Adolescent girls and young women
AIDS	Acquired immune deficiency syndrome
ALHIV	Adolescents living with HIV
ART	Antiretroviral therapy
ARV	Antiretroviral
CD4	Clusters of differentiation 4
CDC	Centers for Disease Control and Prevention
CMIS	Client Management Information System
COREQ	COnsolidated criteria for REporting Qualitative research
DREAMS	Determined, Resilient, Empowered, AIDS-free, Mentored and Safe
EC	Expert client
HBM	Health Belief Model
HCP	Healthcare provider
HCW	Healthcare worker
HIV	Human immune deficiency virus
HTS	HIV testing services
LMICs	Low- and middle-income countries
M2M	Mother to mother
OPD	Outpatient department
OVCs	Orphans and vulnerable children
PEPFAR	President's Emergency Plan for AIDS Relief
PHU	Public health unit
SMS	Short Message Service
SRH	Sexual and reproductive health
SSA	Sub-Saharan Africa
TB	Tuberculosis
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNICEF	United Nations Children's Fund
WHO	World Health Organization

# CHAPTER 1

## INTRODUCTION

### **1.1. Epidemiology of Adolescents Living with HIV**

Adolescents living with HIV (ALHIV) are a growing population; globally, an estimated 39 million people were living with HIV in 2022, of which 2.21 million were adolescents between 10 and 19 years of age (UNAIDS, 2023; UNICEF, 2022). Eighty percent (80%) of the 2.21 million adolescents living with HIV reside in Sub-Saharan Africa (Belle & Gamedze, 2019; Pettifor et al., 2018). Most of these adolescents acquired HIV from their mothers in utero, during delivery, or through breastfeeding, while others got it through unsafe sexual behavior (WHO, 2014). In sub-Saharan Africa, females were the most affected, where six in seven new HIV infections occurred among adolescent girls aged 15 – 19 (UNAIDS, 2023; UNICEF, 2022).

In Eswatini (formerly Swaziland), HIV is a public health challenge with a prevalence of 27% among adolescents and adults aged 15 to 49 years old (Eswatini Ministry of Health, 2019; Whiteside et al., 2017). HIV prevalence in early adolescents (10–14 years) is 3% for both sexes. Late adolescents (15 – 19 years) prevalence is higher at 5% and 3% for girls and boys, respectively (Eswatini Ministry of Health, 2019). In 2021, 6,900 individuals composed of children, adolescents, and adults were newly infected with HIV in Eswatini whilst 2,400 deaths were due to AIDS among individuals aged 15 and above (UNAIDS, 2022).

The following factors contribute to adolescents' vulnerability to HIV in Eswatini: intergenerational sex, poverty, high HIV prevalence, transactional sex (non-marital, non-commercial sexual relationships motivated by an implicit assumption that sex will be

exchanged for material support or other benefits, not sex work), sub-optimal knowledge about HIV risk prevention, substance use, sexually transmitted infections, and unsafe sexual behaviors (Belle & Gamedze, 2019). The number of ALHIV is likely to increase because of unsafe sexual behaviors among adolescents (Agyemang et al., 2020). This is supported by a cross-sectional study conducted in Eswatini whereby adolescents aged 15–19 years (64.1%, n =153) did not use condoms at the first sexual encounter and only 29% of adolescent males and 20% of adolescent females report consistent condom use (Kangmennaang et al., 2019).

Compounding their vulnerability to HIV, ALHIV usually have poorer access to lifesaving and universally available antiretroviral (ARV) treatments than adults (Castelnuovo et al., 2018; Chaudhury et al., 2018; Natukunda et al., 2019). As a result, ALHIV are at substantial risk of adverse health outcomes including death, HIV disease progression (Chaudhury et al., 2018; Hlophe et al., 2022; Natukunda et al., 2019), mental illness, and neurocognitive deficits (Musindo et al., 2022). Even though access to life-saving antiretroviral therapy has been expanded globally, HIV mortality continues to rise among adolescents (WHO, 2021). A unified effort to improve the health outcomes of adolescents living with the HIV pandemic is required (Armstrong et al., 2018; Hamzah & Hamlyn, 2018).

## **1.2. Models of HIV Healthcare Services Targeting ALHIV in Africa**

The models of care for ALHIV vary between countries in Africa. The traditional model of care for ALHIV is the treatment of HIV-positive individuals in regular healthcare facilities. In regular healthcare centers, a separate clinic or structure is designated for HIV care and management (stand-alone HIV clinics) (Ahmed et al., 2022;

Zakumumpa et al., 2018). South Africa is the only country where adolescent clinics (13–19-year-old patients) have designated days to receive care (Woollett et al., 2021). The clinic staff receive training on adolescent development and HIV-specific requirements for young people. Topics include disclosure, adherence, retention in care, and supportive referral. This is observed in five clinics in Johannesburg. The rationale is to fight the stigma associated with HIV among regular healthcare service users, on the other, providers of HIV services are more responsive to the specific needs of HIV individuals. The clinic staff understand and respond to adolescent health and developmental needs. For example, ALHIV recommend scheduling after school appointments or Fridays as they break off early from school. This model of care enhances ALHIV’s access to treatment and retention in care (Woollett et al., 2021).

Most other Sub-Saharan African countries (Eswatini, Uganda, South Africa, Malawi, Lesotho, Botswana, Tanzania, Namibia, etc.) are utilizing a Teen Club model of care (Mark et al., 2019). In Eswatini, Teen Clubs are facilitated by expert clients (a lay health worker who is HIV+ and has openly declared their status) and a nurse from partners of the Ministry of Health in a chosen health center within a specific catchment area (Ministry of Health et al., 2018). Expert clients (ECs) undergo an intensive week-long training on communication, counseling skills, treatment adherence, stigma, disclosure, and HIV linkage to care. Expert clients help ALHIV with disclosure skills, acting as role models, health facility navigation, resolving adherence challenges, fostering resilience and independence. Expert clients play a crucial role in the promotion of health among ALHIV in Eswatini. They close the gap between the community and the healthcare system. For example, ECs re-engage adolescents who are lost to follow-up in HIV care. In addition, ECs prevent reinfection and onward HIV transmission among adolescents by

conducting community-based adherence support and sexual health education. Hence, ECs are vital to improving the quality and efficiency of HIV health service delivery by collaborating with nurses to address adolescent-specific health needs (Ahmed et al., 2022). The Teen Club support meetings do not occur during normal working days (Monday-Friday) but once a month on a Saturday (Ministry of Health et al., 2018).

The first Teen Club was started by Baylor College of Medicine Eswatini in collaboration with the Ministry of Health in 2006 for ALHIV (Ministry of Health et al., 2018). Its core function is to empower ALHIV to live positively and successfully while transitioning into adulthood (Ahmed et al., 2022). The empowerment is achieved by teaching life skills, fostering relationships, opening discussions about HIV, and building confidence among ALHIV. Teen Clubs are a lifeline for ALHIV in Eswatini because it is a haven for adolescents, who rely on their club leaders and each other for psychological and social support. ALHIV who are enrolled in Teen Clubs pick up their ART during their monthly meetings. Mental health services are only provided to adolescents experiencing adherence problems (Ministry of Health et al., 2018).

Teen Clubs come with challenges that threaten their sustainability and efficacy. Some Teen Clubs' membership can sometimes be abruptly interrupted leaving ALHIV feeling abandoned. Teen Clubs with no food or transport reimbursements have poor attendance and declining enrollment (Ministry of Health et al., 2018). Furthermore, Teen Clubs are not integrated into existing healthcare services. Sometimes adolescents who fall sick, accidentally run out of drugs, require sexual and reproductive health (SRH) services, miss drug pick-up dates, or are hospitalized face challenges using regular health centers (Ministry of Health et al., 2018).

### **1.3. Motivation for the Study**

Before 2020, all United Nations (UN) Member States were working towards reaching the UNAIDS 90-90-90 targets which ended in 2020. The first 90 states that 90% of people living with HIV should know their status, the second 90 states that 90% of people testing positive for HIV should be on ART, and the last 90 states that 90% of persons on ART should be virally suppressed. As the world moves from the UN 90-90-90 cascade of care to the 95-95-95 cascade of care to end by 2030, improving access to HIV healthcare services for ALHIV is essential. Adolescents living with HIV cannot be left behind if the world is to achieve the Fast Track: 95-95-95 and HIV epidemic control by 2030. The new cascade of care targets that should be achieved by 2030: 95% of people HIV positive should know their HIV status, 95% of people testing positive for HIV should be on ART and 95% of those should be virally suppressed (Ehrenkranz et al., 2021; UNAIDS, 2014, 2015). Globally, the inadequate engagement with HIV healthcare services among ALHIV means that adolescents are trailing behind in both the second and third 95 of the UNAIDS, whereby 95% of people testing positive for HIV should be on ART and 95% of those people should be virally suppressed (Maena et al., 2021). To achieve HIV epidemic control all ALHIV should use, be adherent to treatment, and be retained in care. By so doing, ART will prevent morbidity, mortality, and new HIV transmissions (Lebelonyane et al., 2021). For Eswatini to reach its target of 85% reduction in new infections by 2030, ALHIV should be engaged in all forms of health services, particularly HIV-related services (Minnery et al., 2020).

In Eswatini, there is no specific HIV data set that captures the 10 – 19 years of age. Therefore, there is no data on the number of adolescents living with HIV, adolescents on ART, and those who are virally suppressed in Eswatini other than those 15-19 years

only. Again, local aggregated data on the UNAIDS cascade of care is for adults aged 15-49 years old (Eswatini Ministry of Health, 2019; UNAIDS, 2022).

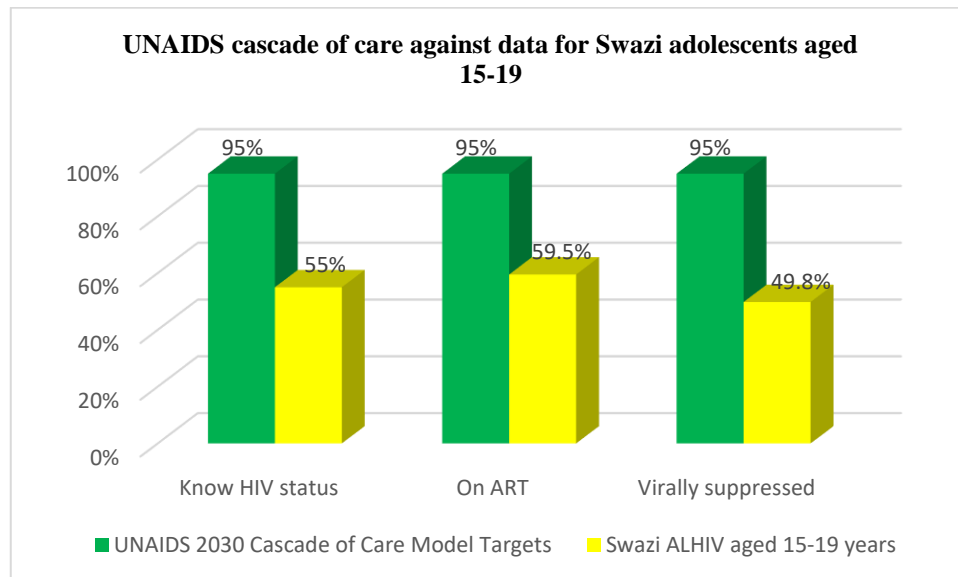


Figure 1. UNAIDS cascade of care against data for Swazi adolescents aged 15-19 (Eswatini Ministry of Health, 2019).

#### 1.4. Problem Statement

There are several touch points where adolescents living with HIV have access challenges to HIV healthcare services. It is well-known that adolescents living with HIV often struggle to maintain sustained utilization of HIV services (Audi et al., 2021; Foster et al., 2020). The suboptimal utilization of HIV services by ALHIV remains a significant challenge in Eswatini despite free access to all HIV services for all people (Ahmed et al., 2022; Becker et al., 2020; Jung et al., 2022).

In Eswatini, routinely collected data on viral load monitoring shows that ALHIV are more likely to have uncontrolled HIV. This is likely associated with poor access to HIV services leading to insufficient treatment adherence among this population (Ahmed et al., 2022; Jobanputra et al., 2015). This finding is corroborated by results from the



Swaziland HIV Incidence Measurement Survey that only 49.8% of adolescents aged 15–19 years are virally suppressed compared to 76.1% of adults (Eswatini Ministry of Health, 2019).

Previous studies explored general experiences of ALHIV with a limited focus on access to HIV healthcare services. The unmet HIV health needs among adolescents exist amidst service availability because healthcare services are not responsive to the evolving health needs of adolescents (Slogrove et al., 2018). Consequently, adolescents may continue to have poor health outcomes despite the availability of life-saving HIV services. Utilization of HIV health services among ALHIV is still a major public health concern thus understanding their HIV health-related needs is crucial for effective programming (Chem et al., 2022).

The purpose of this study is to explore factors influencing access to HIV healthcare services among adolescents living with HIV in an HIV-designated healthcare center in Eswatini using the Lévesque’s conceptual framework of access to healthcare.

### **1.5. Study Objectives**

The specific objectives include:

1. To describe health system factors that facilitate and impede access to HIV services for ALHIV including: approachability, acceptability, availability and accommodation, affordability, and appropriateness.
2. To examine the facilitators and barriers that ALHIV encounter to access HIV care:
  - First, in terms of their ability to perceive the need for HIV care
  - Second, in terms of their ability to seek HIV care
  - Third, in terms of their ability to reach HIV care

- Fourth, in terms of their ability to pay for HIV care
  - Fifth, in terms of their ability to engage in HIV care
3. To gather recommendations from ALHIV and their healthcare providers for improving access to HIV services

## CHAPTER 2

### LITERATURE REVIEW

A systematic review of studies conducted in 2015-2019 in low- and middle-income countries found that ALHIV have suboptimal utilization of HIV services which culminated in poorer ART adherence and viral suppression outcomes than all other age groups. Sadly, low- and middle-income countries (LMICs) have the highest burden of adolescents living with HIV. Furthermore, HIV-infected adolescents in LMICs continue to face numerous challenges regarding ART adherence and viral suppression (Reif et al., 2020). Furthermore, ALHIV are still underserved by national HIV programs worldwide (Munyayi & van Wyk, 2020). There is a lower rate of immunological recovery and viral suppression in adolescents living with HIV in sub-Saharan Africa when compared with adults (Villiera et al., 2022). The successful suppression of the virus and improvement of quality of life in ALHIV require optimum access to HIV services and ultimately adherence to ART (Hlophe et al., 2022).

#### **2.1. Conceptual framework: Levesque's Conceptual Framework of Access to Healthcare Services**

This study uses Levesque's conceptual framework of access to healthcare to identify the reported challenges in the literature related to the different dimensions of access from the health system/health provider's perspective and the adolescents' perception of access (Levesque et al., 2013). Levesque et al. (2013) define access as an opportunity to identify, seek, reach, and obtain appropriate healthcare in situations of perceived need for care. Access starts with ALHIV recognizing their needs and ends when they have received care that appropriately meets their health and well-being needs. In this

way, if there are unmet health needs, then the services are not fully accessible (Levesque et al., 2013).

The Levesque's framework has five dimensions for access. Each dimension is paired with characteristics of healthcare services and the corresponding abilities of ALHIV as determinants of access (Levesque et al., 2013). The key attributes of the health care system are approachability, acceptability, availability and accommodation, affordability, and appropriateness. Furthermore, it postulates five corresponding capabilities of ALHIV: the ability to perceive, the ability to seek, the ability to reach, the ability to pay, and the ability to engage (Fradgley et al., 2015; Ward et al., 2015). Levesque's conceptual framework of access to healthcare is comprehensive and dynamic hence it captures all relevant factors that might impact access. Health systems, institutions, organizations, and providers are viewed from a multilevel perspective. Individuals, households, communities, and populations are also considered in the framework (Ishioka, 2022; Levesque et al., 2013). Levesque's conceptual framework has been used in several qualitative studies investigating healthcare access or utilization (Fradgley et al., 2015; Ward et al., 2015).

Consistent with a body of knowledge, this framework has been largely used to evaluate access to primary care (Fradgley et al., 2015; Ward et al., 2015). The framework considers the influence of people who provide healthcare services as well as those who utilize the services (Levesque et al., 2013). Conversely, some frameworks conceptualize healthcare access or usage by paying more attention to the population and ignoring the healthcare system and healthcare providers. For example, the Andersen Behavioural Model of Healthcare Access conceptualizes access in terms of a population's characteristics: their predisposing factors (attitudes, beliefs, sociodemographic); need

factors (objective and subjective needs), and enabling factors (resources enabling access to and use of healthcare services). In its basic terms, the Andersen model views access as entry into the health care system which is narrow in scope (Carroll et al., 2022). The Levesque's framework has the advantage of considering both health system perspectives on access through its dimensions as well as the perspectives of the population/patients on access through their abilities (Cu et al., 2021).

Obstacles to accessing befitting care can happen at any period from before somebody seeks care to when they are obtaining it (Corcadden et al., 2017). World Health Organization member states are working hard to improve access to healthcare through Universal Healthcare Coverage (Cu et al., 2021). This is particularly true for HIV prevention and control, where there is Test & Start/Treat All (Adams & Zamberia, 2017; Yotebieng et al., 2019). To adequately address the problems of HIV healthcare access, the recognition of all the dimensions and complexities of healthcare access is vital (Cu et al., 2021).

### ***2.1.1. Barriers to Perceiving the Need for HIV Care and the Approachability of Healthcare***

Approachability is the extent to which people with health needs can identify that some form of services exists, that services are reachable, and positively impact their health. More importantly, it is how friendly, reachable, accepting, and open to the needs of ALHIV and how impactful are the healthcare system/health providers. Again, the approachability of health services also refers to the provider's efforts to provide information and educate patients about their services. It is associated with transparency, outreach, and information provision (Levesque et al., 2013).

The ability to perceive the need is defined as the capacity of a person to realize the need to seek care. When services are approachable, a person ought to have the ability to perceive their needs and desire the health care service (Embleton et al., 2021; Levesque et al., 2013). A patient's ability to recognize the need for care is usually the first step in their healthcare journey. Adolescents living with HIV do not always recognize the need for care because of the perceived low severity of HIV (Galea et al., 2018). Other ALHIV lack awareness, lack education about HIV, do not fully understand why they are taking ART, and are disinterested in care (felt depressed or overwhelmed) (Audi et al., 2021, Kim et al., 2017; Maskew et al., 2016). Late and poor disclosure of HIV status to adolescents also contributes to the unperceived need for HIV care (Kim et al., 2017).

### ***2.1.2. Barriers to Seeking HIV Care and Acceptability of Health Services***

A person's acceptance of a service is determined by cultural and social factors (e.g., the gender or social group of the providers, beliefs associated with medical systems) as well as their judgment of whether the care is appropriate. Social and cultural factors, norms, and professional values affect the acceptability of healthcare services and providers. Acceptability is when ALHIV values HIV healthcare services and eventually accepts to use them (Levesque et al., 2013). The capacity to access HIV care correlates with social and cultural elements that affect services. It determines whether individuals will accept services that do not conflict with their cherished cultural, societal, or personal values in order to access health services without feeling unsafe or discomfort. The capacity to seek health care also relates to the concept of personal autonomy and the capacity to choose to seek care (Levesque et al., 2013). Clearly, in the case of ALHIV, some will be able to seek care on their own, while others may need an advocate,

particularly a professional care worker (Schwarz et al., 2022). For instance, the developmental and growth challenges experienced by ALHIV, such as their desire to experience sex, parenthood, love, and be loved in return impair their capacity and self-governance to seek healthcare when needed and be informed about options.

Adolescents living with HIV do not recognize health services as acceptable and hence do not seek help (Chem et al., 2022). Furthermore, health workers' hostile and punitive attitudes toward adolescents who get HIV through unsafe sex deter adolescents from seeking healthcare and remaining in care (Sherr et al., 2018). Adolescents living with HIV do not seek HIV healthcare services because they are afraid that friends/school will notice their visits (Maskew et al., 2016). Moreover, ALHIV fear stigma from people inside their homes particularly extended families who may notice their visit to a health facility (Kim et al., 2017). Adolescents living with HIV fear disclosing their HIV status to different healthcare providers every time they seek care (Audi et al., 2021).

### ***2.1.3. Barriers to Reaching HIV Health Care and Availability and Accommodation of Health Services***

Availability and accommodation are when healthcare providers and services are reachable. This necessitates that health services are physically available with sufficient resources and capacity to provide services. The geographic location of services (rural, urban, decentralization) and providers (availability of qualified providers) affect the degree of availability and accommodation of healthcare (Embleton et al., 2021; Levesque et al., 2013).

The ability to reach is a person's mobility, availability of transportation, capacity to leave school to reach care, and knowledge about how to tangibly reach healthcare facilities and providers (Embleton et al., 2021; Levesque et al., 2013). In the context of

adolescents living with HIV, the availability of services refers to the general existence of health services and healthcare providers. Furthermore, the health services and healthcare providers' accessibility to patients, both physically and in a timely manner are considered (Levesque et al., 2013). The lack of responsive health services renders health services unavailable and unaccommodating for ALHIV. For example, lack of specialized service providers for ALHIV (Maskew et al., 2016).

The lack of service providers with the appropriate knowledge and skills to provide developmentally appropriate care is one of the greatest gaps in adolescent HIV care. The lack of qualified healthcare providers for ALHIV affects the quality of HIV counseling, the provision of ongoing supportive counseling, addressing care, and treatment adherence issues (Hayfron-Benjamin et al., 2020; Maskew et al., 2016). This is further exacerbated by the unavailability of adolescent-friendly services, long waiting times, negative health provider attitudes towards ALHIV when they miss ARVs, long facility turnaround time for ARV refills, lack of information about SRH, suboptimal mental health support to overcome HIV-induced depression and stress (Chem et al., 2022).

#### ***2.1.4. Barriers to Utilizing Care and Barriers to the Ability to Pay (Affordability)***

Healthcare utilization is influenced by its cost. Affordability refers to the state of HIV healthcare services being cheap enough for ALHIV to be able to pay for them. For example, HIV services in Eswatini are affordable to all ALHIV in monetary terms. The ability to pay is a person's capability to pay for services (transportation, service fee) and spend time (taking time off) to use needed health services without enduring financial hardship (Davy et al., 2016; Embleton et al., 2021; Haj-Younes et al., 2022; Levesque et



al., 2013). Lack of transportation money to the service center, time conflict, and poverty are examples of barriers to utilizing HIV care (Audi et al., 2021). Some ALHIV lack the financial resources to pay for transportation to a clinic without outreach clinics (Chem et al., 2022). In the context of adolescents who have HIV, usually have higher healthcare waiting times (Levesque et al., 2013) which conflict with restrictive school policies (Maskew et al., 2016).

#### ***2.1.5. Barriers to the Ability to Engage as an Empowered Patient with the Health System and Appropriateness of HIV Care***

Appropriateness of care is reflected in the fit between treatment and the adolescents' needs, its timeliness, coordination, and its quality. The appropriateness of care further refers to the continuity of care, and multidisciplinary cooperation. Therefore, the utilization of only poor-quality HIV services is seen as a restriction on access to health care. The ability to engage in healthcare refers to a patient's ability to participate and be involved in the decision-making process regarding their HIV care (Davy et al., 2016; Levesque et al., 2013). Communication, self-efficacy, self-managing, and health literacy are all essential elements of this dimension. It is also important that ALHIV receive care that is appropriate to their resources and capacities (Levesque et al., 2013). The health outcomes of adolescents living with HIV rely heavily on the appropriateness of care and their ability to engage in health care. The ability of ALHIV to engage in health care correlates with their participation in decision-making and their compliance in therapy (Davy et al., 2016; Levesque et al., 2013).

The inconsistent and uncoordinated care pathways in the care of ALHIV particularly, in transition phases lead to gaps in HIV care and reduced adherence to therapy. There is no tracking of adolescents' transition from pediatric to adulthood model

of HIV care thus leading to some adolescents falling within the cracks. Again, suboptimal psychosocial support and lack of empowerment for ALHIV within health facilities make adolescents susceptible to self-stigma and social stigma within the healthcare system. In Eswatini, the stigma is further worsened by the inability of ALHIV to accept their HIV diagnosis and the unpredictable support from healthcare providers (Chem et al., 2022).

Adolescents living with HIV are faced with challenges, such as limited involvement in their care and poor disclosure of HIV status rendering HIV services inappropriate. In Temeke Regional Referral Hospital, Tanzania, adolescents stated that they were not consulted in the decision-making process and were sad about their limited participation in testing for HIV and enrollment in care (Joseph et al., 2022). Treatment fatigue causes disengagement from HIV care (Maskew et al., 2016).

Health workers admitted that they cannot adequately provide adolescent-friendly health services. Additionally, health workers noted that adolescent-friendly services were either non-existent or poorly executed in HIV treatment facilities (Chem et al., 2022). The lack of trained staff to manage ALHIV and poor implementation of adolescent-friendly services are leading barriers to integrative adolescent services. Healthcare services are available most of the time, however, healthcare workers' attitudes and competencies in working with ALHIV render the services inaccessible and inappropriate (Chem et al., 2022; WHO, 2019; Woollett et al., 2021). Both the ability to perceive and the ability to engage in healthcare require trust. Trust is essential for both perception and engagement in healthcare. Participant distrust of the healthcare system was correlated with negative experiences, discrimination perception, poor communication, lack of time, and, to some extent, perceived provider inexperience (Chem et al., 2022; Schwarz et al., 2022).

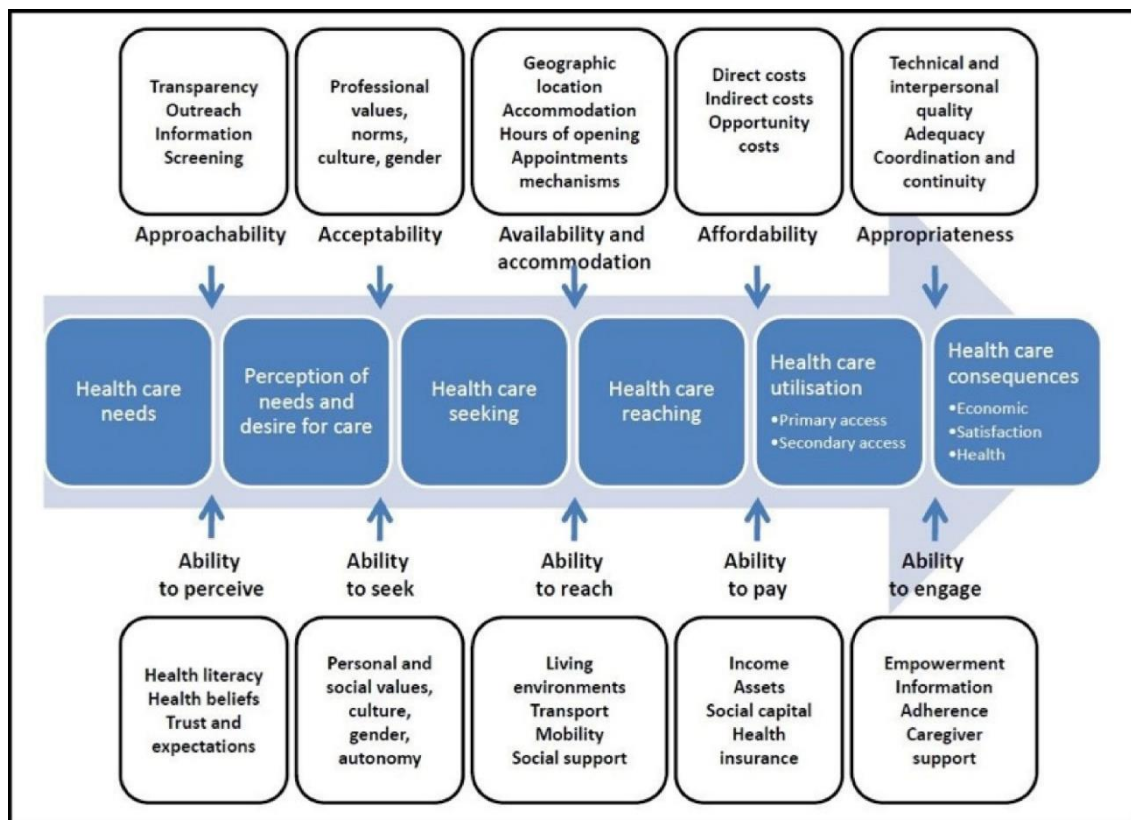


Figure 2. Levesque's Conceptual Framework of Access to Healthcare Services

The factors that lead to poor utilization of HIV services are complex and ever-changing. It is, therefore, important to continually evaluate them throughout one's life, especially during the teenage and young adult years (Yusuf & Agwu, 2021).

# CHAPTER 3

## METHODOLOGY

This chapter outlines the research methods that were used to conduct the study. This section explains how the necessary data and information were collected to address the research objectives. It also discusses the presentation and analysis of the collected data.

### **3.1. Research Design and Research Approach**

The study used an exploratory-descriptive qualitative design. The subjective perceptions of the participants formed the core data of the study; hence it needed a method that would deal with the topic in an exploratory nature. This design ensured the description and provision of a rich account of the HIV healthcare access issues experienced (Polit & Beck, 2017) by ALHIV in Eswatini based on the Levesque dimensions of access as a framework.

### **3.2. Ethical Considerations**

Ethical clearance and approval of the study were granted by the American University of Beirut Institutional Review Board and the Eswatini Health and Human Research Review Board. Permission to access the study site was requested from the health facility matron (management) through writing. Efforts were made to keep study-related information confidential. All collected data were treated with strict confidentiality. The interviews were conducted in a private room and no names or identifiers were collected. Throughout

the study, participants were identified by a unique number to conceal their identities. Participants were informed that study participation was voluntary, and they had the right to withdraw at any point if they felt uncomfortable or they simply so wished. No names of participants will be disclosed in any reports or presentations of this research. Data will only be reported in aggregate. All transcripts were kept on a password-protected computer. The audiotapes were immediately transcribed and deleted from the records. After the conclusion of the study, the principal investigator retained all original study data in a secure location for at least three years to meet institutional archiving requirements. After this period, data will be responsibly destroyed. The principles of autonomy, respect for persons, beneficence, maleficence, and justice (Polit & Beck, 2017) guided the conduction of the study.

There were minimal risks for being in the study, participants felt uncomfortable responding to some personal questions. Participants might have been referred to the mental health and psychosocial service for psychosocial support within the health center in cooperation with the legal guardian/parent or just the participant when 18 years and above. This would have happened when a participant showed excessive emotions (uncontrollable weeping) during the discussion of some questions and then emotional breakdown.

### **3.3. Setting of the Study**

The study was conducted in the Lubombo region at Sithobela Rural Health Centre. The Lubombo region is the largest of four regions in Eswatini. The region has a population of about 212,531 people (Swaziland Central Statistical Office, 2017). Its HIV prevalence for individuals aged 15-49 years is 29.4% compared to the national prevalence

of 27% (Justman et al., 2017; Swaziland Central Statistical Office, 2017). The region has diminished access to services and poor transportation systems. Poverty impacts the population's capacity to seek health services in health facilities and thus there is a higher reliance on mobile services and community outreaches (PEPFAR, 2021).

The health facility where the participants were sampled provides a wide range of primary healthcare services. The services include curative services for minor ailments, child welfare services, laboratory, X-ray imaging, pharmacy, mini operation theatre, antenatal care, family planning, inpatient wards, maternity services, a tuberculosis clinic, and an ART clinic. The health center had two medical doctors, 53 nurses, three pharmacists, six expert clients, one case linkage officer, three HIV testing service (HTS) counselors, one adolescent girls and young women (AGYW) navigator, two data clerks, one AGYW nurse, one cervical cancer nurse, two mentor mothers, three radiographers, four laboratory personnel and two TB screening officer. The health center had 2 238 as a mean number of patients seen at ART Clinic monthly, and 3 743 mean number of patients seen monthly at the Health Center's OPD. The Health Center serviced about 921 adolescents living with HIV in total. The Health Center has a catchment population of 43 562 people in this rural and low-income community of Sithobela.

### **3.4. Sampling Procedure**

A purposive maximum variation sampling approach was used to ensure including adolescents with good and poor treatment adherence; gender, and age distribution (12-19 years). Healthcare providers responsible for the welfare of ALHIV were sampled using convenience sampling.

The inclusion and exclusion criteria:

- For ALHIV: adolescents living with HIV aged 12 to 19 years, conversant in either siSwati or English, and on ART for at least 6 months before the start of the study.
- For healthcare providers: HCPs involved in the care of ALHIV in the healthcare center and conversant in either siSwati or English.
- The exclusion criteria for adolescents were individuals less than 12 and older than 19 years, not HIV positive, unaware of HIV status, and on ART for less than 6 months before the start of the study.
- The exclusion criteria for healthcare providers were healthcare providers not involved in the care of ALHIV and over 60 years (60 years is the pensionable age).

The sample size was determined by data saturation.

### **3.5. Recruitment of Participants**

The primary researcher introduced the study and its purpose to healthcare providers who were responsible for the welfare of adolescents living with HIV. The primary researcher then invited the healthcare providers to participate in the study when interested. Interested healthcare providers were told that they could come to consultation room 3 within the ART clinic during their own time. An ethically approved healthcare provider's recruitment poster was posted on the center's notice board and staff WhatsApp group. On another note, the healthcare providers at the ART clinic were given the eligibility and exclusion criteria for ALHIV. To ensure confidentiality, the person responsible for accessing the system of health records for ALHIV was the only one who used a teen club registry and the Client Management Information System (CMIS) to sample adolescents meeting the eligibility criteria. During the adolescents' ART refill,

the person responsible for accessing the system, informed the pre-sampled adolescents (12-19 years old) that there was a study that sought to understand HIV healthcare-related access challenges among ALHIV.

The person responsible for accessing the system of health records for adolescents living with HIV told the ALHIV that anyone who would like to know more about the study may go to consultation room 3 within the ART Clinic. The primary researcher was present at the research site Monday to Friday (11:00 a.m. to 3:00 p.m. South Africa Standard Time), twice on a Saturday. When adolescents living with HIV came to the private consultation room 3, more information was given and those who wanted to participate in the study were invited. When no next of kin was available on the day of ART Refill for ALHIV aged 12-17 years old and the participant was keen on participating; the participant independently entrusted someone to be his/her witness and signed the consent. The witness was not part of the research team and was not a healthcare worker at the research site. Therefore, ALHIV aged 12-17 years were not recruited by the primary researcher without signed parental consent.

### **3.6. Pilot Testing the Topic Guide**

The data collector received training on how to conduct interviews. A topic guide was developed based on the Levesque's Conceptual Framework of Access to Health Care by exploring factors that facilitate and impede the adolescents' ability to access HIV services. The topic guide was piloted with three participants meeting the eligibility criteria to make sure that we were capturing all the components of the study in a feasible time. Moreover, the pilot study provided the researcher with practical experience to boost confidence and competence (Wray et al., 2017).



There were two topic guides, one for ALHIV (Appendix 1, p. 83) and the other for healthcare providers (Appendix 2, p. 84). Using the Levesque's conceptual framework, we probed for the following in ALHIV: their knowledge about the importance and value of ART to them, the kind of support they get from their families/communities, facilitators, and barriers for reaching HIV services, sources of fund to pay for HIV care and what had kept them in treatment. Recommendations for each barrier mentioned were asked.

For healthcare providers, we probed about measures for making the HIV services approachable, challenges that could make the center/HCP unapproachable, training they received on dealing with ALHIV, HIV services that target ALHIV, how the center supports ALHIV, how the center funds HIV services, how the operations and structure of the center promote or impede sustained access to HIV service for ALHIV. Again, recommendations for each identified HIV service issue were asked.

### **3.7. Data Collection**

After obtaining consent (assent for those below 18 years; informed consent for those above 18; and verbal for HCPs) data were collected. Data were collected using in-depth, face-to-face interviews with each participant. The interviews were audio-recorded with the permission of the participants and the legal parents of adolescents aged 12-17 years old. Interviews were conducted in SiSwati, the native language of the participants, as it was easier to express themselves. Each interview took about 24-52 minutes in a private consultation room as indicated above. Interviews were conducted during the day and there were no follow-up interviews. Interviews used a conversational and interactive

style which enabled participants to provide a rich account of their experiences. Interview techniques such as probing, seeking clarification, and summarizing (Smith & Sparkes, 2016) were used to obtain more information from participants.

Data were collected from participants until a point of data saturation was reached. Data were collected from 12 healthcare providers and 15 adolescents living with HIV, we realized that we reached data saturation, that is the point at which collecting more data about a phenomenon yields no new insights (Constantinou et al., 2017; Saunders et al., 2018; Vasileiou et al., 2018).

### **3.8. Data Analysis**

Before data analysis, the transcripts were checked for consistency between the translation from Siswati to English. Simple random sampling was used to sample three out of nine (ALHIV 1...ALHIV 9) adolescents whose recordings were originally in Siswati. Nine pieces of paper were written ALHIV 1, ALHIV 2, ... to ALHIV 9 and then folded. The folded papers were then put in a bowl. After shaking the pieces of paper, a piece of paper was picked, read, not put inside, and then shaken again. This was repeated until three participants' transcripts for spot-checking were selected. Back translation from English to Siswati was done to check for consistency by a language editor fluent in both English and SiSwati. Back translation from English back to SiSwati was done to ensure that there was no loss of meaning.

The researcher then engaged himself with the participants' data and critically reflected on the experiences as described by the participants (Polit & Beck, 2017). The seven stages of the Framework Method were used to manage and analyze the qualitative data. The first stage was a transcription, whereby each audio recording was transcribed

verbatim. Through transcription, the primary researcher familiarized himself with the data. The second stage was the actual familiarization, in this phase, the primary researcher re-listened to the whole interview audio and re-read the transcription. The third stage was coding, whereby the researcher carefully read each transcript line and labeled (code) it based on Levesque's Framework. Stage four was developing a working analytical framework. In the fourth stage, the researcher organized a set of codes into categories that were used to manage and organize the data. Furthermore, the researcher kept track of all the initial code sets used and then applied those codes to all subsequent transcripts uniformly.

The fifth stage was applying the analytical framework. Here the analytical framework was applied by indexing subsequent transcripts using the existing codes and categories (dimensions and abilities from the conceptual framework). Each code was abbreviated and written directly onto the transcripts. The QUIRKOS qualitative software package was used to organize and store the data.

The sixth stage was charting data into a figure of the Levesque's conceptual framework of healthcare access. As a means of charting, the data were summarized by category from each transcript. While charting, the original meanings and feel of the interviewees' words were not changed. The chart included illustrative quotations. The seventh and final stage was data interpretation. By identifying the characteristics of the data and differentiating them from each other. The exploration of relationships involved mapping connections between categories.

### **3.9. Trustworthiness**

The trustworthiness of the study was safeguarded by adhering to the Consolidated criteria for Reporting Qualitative research (COREQ) guidelines. This improves the study's comprehensiveness and credibility by promoting complete and transparent reporting (Simon et al., 2015; Tong et al., 2007). The COREQ checklist is found in Appendix 3 (p. 87).

Again, Lincoln and Guba's framework was used (Lincoln & Guba, 1985). All four criteria in the framework were used: credibility, dependability, transferability, and confirmability to ensure rigor in this study (Morse, 2015).

Credibility ensured the truth of the study findings. It provided a basis that the study findings and conclusions are the perspectives and interpretations of the participants' lived experiences (Forero et al., 2018; Morse, 2015; Noble & Smith, 2015). The criterion of credibility was established by audio recording, verbatim transcription, extended data collection time until data saturation, and keeping comprehensive field notes. Debriefing and review also contributed to the credibility of the study.

Transferability is the extent to which the study findings can be generalized or transferred to other contexts and population groups (Korstjens & Moser, 2018; Sundler et al., 2019). Purposive sampling aided in ensuring transferability by recruiting participants who could provide rich data for the phenomenon under study and quoting participants.

Dependability demanded the reliability of the study to ensure that the study would generate the same results if it was replicated on similar participants in a similar context (Nowell et al., 2017). This was observed by using a topic guide. The researcher gave a comprehensive description of how data were collected, and a complete description of the

methods to be followed when conducting the study. The research process was monitored; the transcripts and findings were discussed and reviewed by the research supervisor.

Confirmability is concerned about the interpretations of the data and conclusions being shaped by the respondents and not by the researcher's bias, motivation, or interest (Lincoln & Guba, 1985). Confirmability was ensured by briefing and by keeping records of the research process for an audit trail. These documents comprised of transcripts, and supervisor feedback documents, such that the documents can be readily accessed when required.

### **3.10. Conclusion**

Understanding the experiences of adolescents living with HIV is crucial in designing adolescent-friendly services, including healthcare transition interventions. The study could bring long-lasting solutions to the under-utilization of healthcare services among adolescents living with HIV.

## CHAPTER 4

### STUDY FINDINGS

In the previous chapter, the research design and methodology were discussed. This chapter presents the findings of the research as they emerged from the data collection and analysis.

#### **4.1. Sample Characteristics**

The sample consisted of 12 healthcare providers working with adolescents living with HIV. Of the 12 healthcare providers, there were three nurses, one medical doctor, three expert clients, one nurse manager in charge of the ART Clinic, one pharmacist, two mentor mothers, and one case linkage officer. The sample also included 15 adolescents living with HIV, eight female and seven male adolescents. Fourteen of the adolescents were perinatally infected with HIV while one was infected behaviorally. At the time of data collection, all the adolescents were aware of their HIV status and had been on ART for more than six months. All the adolescents were in school, both primary and high school. The age of the adolescents ranged from 13 to 18 years.

#### **4.2. Main Study Results**

The study findings as stated in chapter two are presented based on Levesque's Conceptual Framework of Health Care Access. The framework has five domains for the healthcare system/healthcare providers and corresponding five abilities for the healthcare beneficiaries. Each domain will be presented with positive attributes from the healthcare system/healthcare providers that enhance the domain's visibility and success and the

negatives that impede the domain's visibility and success. Similarly, the abilities of the healthcare beneficiaries will be presented as positive domains first followed by negative ones that facilitate and impede their abilities to utilize the healthcare system.

#### ***4.2.1. Approachability of HIV Services and the Ability to Perceive the Need for HIV Care***

Under this domain, the health care system made concerted efforts to improve the visibility of the HIV clinic services through social marketing campaigns targeting both adolescents living with HIV and those who were not as well as their communities.

These campaigns were meant to boost awareness about the services offered including the availability of free ART pills and refill centers spread throughout the community, education, and counseling about compliance with pills' intake, how to live with HIV, and how to reduce the risk of transmission in the community.

HCP 1 indicated:

'We teach the youth living with HIV a lot about the importance of the pills ... We also tell them that for them to live and be adults, they need to continue to take their pill.'

The social marketing campaigns were based in schools and their surrounding communities, in regular clinics, in community events, in Teen Club meetings, and among orphans and vulnerable children (OVCs) living with HIV. Some HCPs indicated:

'We really emphasize the importance of taking pills to the youth and what HIV services we have here. ... we try to have meetings with the mothers during times of Teen Club quarterly ... and market our services for their children.' HCP 3

Some HCPs indicated:

'... sometimes use schools or community halls to talk about our HIV services and help them ...' HCP 5

On the other hand, given that our sample consisted of ALHIV using the HIV services of the center, it was evident that they were able to perceive the need for HIV care. This was a result of the adolescents' health literacy about HIV and ART. This was reflected in their ability to iterate the importance of approaching the center for ART and other HIV services. Most stated that they knew that they needed to take the treatment for their lifetime, the purpose of ART, and its impact on their health condition. Some adolescents said, *'The pills are very important, and I know why... I know they do not cure the virus, but it makes my body's soldiers to be strong and be able to fight other diseases that could make me sick' ...ALHIV 5*. Further, some adolescents perceived the severe consequences should they stop taking their pills. They perceived the treatment as their life savers. They believed that without the treatment they would not reach their dreams as they would die prematurely. This adolescent indicated, *'I also know that if I stop taking the pills, I will not live long, I will be sick, and I can even die without getting my dream...'* ALHIV 8

Conversely, some HCPs indicated that the level of awareness in the community about the importance of HIV services remained limited. They were still *'losing a lot of the children through missed appointments, defaulting, and disengagement from HIV care... HCP 11*.

Even among our ALHIV sample, it was evident from their comments that they were still missing important information about HIV care. This adolescent indicated:

*'I did not think this will have a problem because I take the pills every day when I remember... can you tell me why they are important... Will I have to stop taking the pills at some point in time?... ALHIV 13*.

It also appears that some guardians negatively influenced their adolescents' ability to perceive the need for HIV care. For instance, some HCPs reported that guardians did



not disclose to their children that they had HIV, *'they just say that they're taking pills for a headache or TB' ... HCP 11*

In fact, the biggest challenge that HCPs faced was poor disclosure to adolescents from their guardians. *'You may find that the child lives with the grandmother who knows nothing about the HIV status of the child and the old woman would just remind the child the take his headache pills' ... HCP 1*

Some HCPs reported that some adolescents living with HIV did not accept their HIV status. They were angry and blamed their parents for being HIV-positive. This negative attitude prompted them to miss appointments, and even stop engaging in HIV care.

*'Some of these children are so angry with their parents because they don't understand how they got it' ... HCP 8.*

This anger was echoed by a few of our adolescents living with HIV:

*'You also know that no one is happy about having HIV' ... ALHIV 13*

*'I am going to talk to my mother so she can explain why only me with HIV and the other 8 children do not have HIV' ... ALHIV 12*

#### **4.2.2. Acceptability and Ability to Seek HIV Care**

In addition to being aware and perceiving the need for HIV care, the services need to be appealing to beneficiaries and accessible. The healthcare system had worked on enhancing the ability to seek HIV care through targeted HIV healthcare packages. For example, HCPs reported that they had targeted HIV services for orphans and vulnerable children (OVC) living with HIV. They were given money for transport and food parcels, monthly or bi-monthly. This assistance helped the adolescents to adhere to therapy and to continue taking the treatment like any other adolescent living with HIV. However,

some of the adolescents who were orphans did not receive the OVC HIV healthcare package. Some HCPs indicated:

‘Some of the teenagers are supported with food and bus fare to come for the Teen Club and the support is not there for all constituencies’ ... HCP 5.  
‘The OVCs like coming for the services because they feel loved here’ HCP 7.

Another healthcare package targeted adolescent girls and young women (AGYW), both those with HIV and not. Through this HIV healthcare package, healthcare providers stated that they provided youth-friendly HIV services. Adolescents who had become pregnant and are out of school, but still wanted to go to school were funded to go back to school or helped to make money-generating projects. The AGYW services helped the adolescents not to queue at the ART Clinic. The HCPs reported that the ALHIV got almost all the HIV services in one room at the public health unit within the health center. This helped them not to go around the center thus preventing the risk of accidental disclosure by going to the ART Clinic. *‘In short, now that they have introduced this thing of AGYW I find this thing easy to access services for the youth just because they are being treated specially’ ...HCP 9.*

HCPs reported that they were happy with the AGYW services.

‘So far, we have a high number of adolescents and young women who come for the services at the PHU because they get everything there from the DREAMS Nurse, they don’t have to queue at the OPD’ ... HCP 11

It appears that the population group targeted HIV healthcare packages met the adolescents’ needs and expectations, hence their acceptance of the HIV services and enhanced their ability to seek HIV care. This is echoed by some HCPs who indicated:

‘But the hospital is helping because we now have people who are working with adolescents and the youth... The youth like coming for the services that are for them.’... HCP 6.

Another factor that enhanced the ability to seek HIV care was the family. Adolescents reported that their families reminded them when it was time to go to seek HIV care at the health center and facilitated their commute to the HIV clinic.

‘My mother reminds me that tomorrow you go to the hospital, wakes me, and gives me money for coming here’ ALHIV 15  
‘I do not have both parents, but my uncle helps me to come to the hospital for pills’ ALHIV 1

Health care system factors and adolescent factors that hindered adolescents from seeking HIV care included the age gap between health care providers and beneficiaries and guardians denouncing adolescents for getting HIV. Older HCPs associated HIV infection with sexual activity.

‘I feel like the huge age may have generational gaps, a healthcare worker with 46 years feels like children with 16 years are now having sexual intercourse how come, while when he/she was 16 years did not have sex...’ HCP 6

Hence, they were discriminating against them and stigmatizing them, which made it difficult for the adolescents to seek HIV services. Some of the participants indicated:

‘It is stigma mostly within the healthcare system from those who do not have HIV.’, HCP 6.  
‘We have names like them. I do know how to explain to you but some not good and their look.’, ALHIV 5.

Some guardians denounced the adolescents for acquiring HIV through unsafe sexual behavior and did not support them in seeking HIV care.

‘Some parents denounce them for what they have done in getting HIV.’ HCP 1

#### **4.2.3. Availability and Accommodation and Ability to Reach HIV Care**

As indicated above, the health care system provided several avenues to reach out to teens in order to accommodate their needs and improve their ability to reach HIV care including: Teen Club, favorable geographic location of the health center (good gravel

roads and public transport availability and a short and walkable distance to the Center), supportive scheduling, and skipping the line when in school uniform in mainstream HIV care.

**Teen Club:** The healthcare providers defined a teen club as a peer support group and information-sharing forum for adolescents living with HIV from the ages of *'10 to 20 and above adolescents, and young adults of course like those 21 years are young adults'* HCP 11

In this peer-to-peer support group, HCPs train adolescents to become expert clients. They train them on how to prevent HIV reinfection and transmission, how to take ART, and *'teach them life skills'* HCP 1. Eventually, those expert clients educate their fellow adolescents about those issues. At the same time, those client experts become an avenue for psychosocial support. For example, in the Teen Club, the adolescents can discuss among themselves the challenges they face with HCPs, to freely talk about their lives, and share their social values. There was a reported culture of normalcy in the Teen Club in the sense that the adolescents felt human and non-discriminated against. This HCP said:

*'Teen Club where these teenagers come together, share their experiences, mentor each other, help others to cope and they play together which is kind of a social bubble where they get to know that they're not the only ones living with HIV, and they can still attain their dreams'* HCP 8

The Teen Club was very well received as per HCPs and ALHIVs. Some of the participants said:

*'What I can say is that they like the Teen Club, and those accustomed to the club do not want to miss'* HCP 11

*'I like coming to the teen club ... And no one discriminates against me ... I feel good in the teen club because that is why I relax where I have people who have the same thing that I have when we relax, and I feel myself'* ALHIV 2

**Favorable Geographic Location of Health Center:** The health center had some good gravel roads that were passable even during heavy rains. The roads had good tall bridges that did not overflow. Some areas surrounding the health facility had reliable public transport, despite all the challenges that could be brought about by the weather. They had public transport all day long based on the times in which the transport passed by the center. This made it possible for the beneficiaries to reach the center.

‘The roads are okay because all the cars are moving’ ALHIV 9

‘I come here even when it is raining’ ALHIV 15

In addition, the short and walkable distance to the Center helped the adolescents to easily reach for HIV care.

‘And I'm happy that I'm not very far from the hospital, because from home to here I walk on foot’ ALHIV 5

**Supportive Scheduling from Healthcare Providers:** HCPs stated that they provided supportive scheduling to adolescents. They involved adolescents in their scheduling or their appointment mechanisms.

‘After giving them the care, I will have a range of dates on which I can appoint them so I will ask them to choose the date depending on the amount of stock that they will still be having’ HCP 10

Some were asked to ‘*come very early before they go to school*’ HCP 2, while others were allowed to come on Saturday during the Teen Club to avoid missing school. Some healthcare providers indicated:

‘For example, we can recommend that if he cannot come during the week for blood collection he can come during the weekend and lean on the Teen Club, just for the help not for the Teen Club services.’, HCP 1.

**Skipping Line When in School Uniform:** By so doing, it helped the adolescents to quickly reach HIV care.

*'When they are in uniform, we ask them to come up front to take and go to school' HCP*

12. The HCPs reported that most adolescents liked this accommodation.

*'For schoolchildren, they do not stand in the line, we just fast-track their service, on uniform only' HCP 7*

The ability to reach HIV services was also facilitated by **support from schools to adolescents**. Some adolescents reported that their schools allowed them to go to the health center during breaks, especially schools close to the health center. Some schools allowed adolescents even to be absent for the entire day. Some HCPs said, *'Sometimes the children come to get their stuff during their break or lunch because they arranged with a nurse and their school allow them...'*, HCP 11. Some adolescents said *'So, today I got the permission for not going to school from my class teacher to come here.'*, ALHIV 1.

When the adolescents had tests that conflicted with their time for coming to the center, the teacher *'helps [me] to write the test during sports days on Mondays in the afternoon'* ALHIV 1. This helped the students to be able to attend to their HIV services and be able to reach the center.

Despite all the HIV services and accommodation provided by the health center, there were issues with accommodation and the adolescents' ability to reach HIV care. Merging adolescents with mainstream HIV care, community drug distribution, limited options for refill dates, for some it was the unfavorable location of the Health Center, and inadequate social support for adolescents were the barriers to the adolescents' ability to reach HIV care.

**Mainstream HIV care:** The mainstream HIV care service was for all patients living with HIV and taking ART irrespective of age and gender, usually in a standalone ART Clinic. The HCPs reported that adolescents did not like the mainstream because when they were queuing with adults, and were *'asked questions about their sickness'* HCP 8, and sometimes they saw their neighbors or relatives in the ART Clinic, which made them *'turn back... I did come but there was someone in the ART Clinic. I did not want to see her there'* HCP 10 and more importantly resulted in accidental HIV disclosure.

**Community drug distribution program:** The health care center had a community drug distribution program or community commodity distribution for ART. The community-drug distribution point is a care model for clinically stable patients in the community. The HCPs stated that the program was designed to make ART delivery more efficient for the health system and provide appropriate support to encourage long-term retention of patients. *'The children who have issues of reaching the hospital, we normally bring drugs to them through the community at visit'* HCP 8

However, HCPs reported that this service was not liked by most adolescents because it also risked accidental disclosure. This healthcare provider said:

*'Adolescents do not like coming to the community because they do not want to be seen...'* HCP 6

**Limited Options for Refill Dates:** The healthcare providers said that there were limited options for refill dates for the adolescents due to having one Saturday, often the third week of a month, for Teen Club and ART refill dates, which at times, conflicted with school time.

*'I only have problems when I have tests or classes on Saturdays because that means I cannot come for Teen Clubs, so I have to go to school' ALHIV 11.* Imposing appointment dates was also stated as not providing options for accessing the service.

'The client will not come you will say this one didn't come and yet you are the one who imposed your dates on him/her' HCP 10

**Unfavorable Location of the Health Center:** Despite the multiple accommodations stated above, there were still some unfavorable locations of the health center. Both HCPs and ALHIVs reported that some roads were impassable when it rained heavily due to slippery mud and water moving over bridges in some rivers. This was particularly faced by adolescents who lived far from the health center.

'When it is heavily raining sometimes the rivers are full and the buses are not available, I cannot come here' ALHIV 2

Having the ART Clinic by the gate as a standalone clinic was not favorable to both HCPs and ALHIVs as this makes it easily noticeable that the patient is HIV positive, hence fear of identity disclosure and lack of privacy.

'To speak the truth, I do not like it because people see that I have HIV when I come here' ALHIV 7

'The ART Clinic is by the gate and adolescents do not like to be seen' HCP 10

**Inadequate Social Support for Adolescents:** The participants reported that the community was judgmental of those adolescents and thus there was a need to

*'...to educate the community' [ as this] 'could be helpful because they can help support and make it easier for the children to come.'*, HCP 11.

#### **4.2.4. Affordability and Ability to Pay for HIV Care**

The healthcare system facilitates the affordability of HIV services through **Government-subsidized services**. Both the healthcare providers and adolescents reported that all HIV



healthcare services were free of charge for adolescents. The adolescents only paid for their transportation to the center, not for the HIV services.

ALHIV 5: ... I don't pay for getting the pills...

HCP 1: ... The children do not pay for the HIV services, it partners with the government that funds the HIV services...

The adolescents' ability to pay for HIV care was enhanced by financial support from their families and income from their work. The financial support from their families helped the adolescents to afford bus fare to the Health Center. Some of the adolescents reported that their grandparents got money from the government's elderly grants, which enabled them to pay for the transport. Some adolescents said '*... grandmother get money for grandfathers and grandmothers.*', ALHIV 11.

Some healthcare providers noted that some of the adolescents worked to make money.

'They tell me that they do hairdressing, hoeing, and things like that to make money' HCP 2

Despite all HIV services being made free to all people living with HIV, some adolescents still cannot afford access to HIV care. **Poverty** was the major barrier. Some HCPs said, '*We need to remember that almost 60% of the peoples here in Swaziland live in poverty.*', HCP 5, hence some do not have the money for the bus fare to come to the clinic. Some adolescents indicated '*I sometimes do not have money to come to the hospital which is why I am not in the Teen Club.*', ALHIV 1.

Some adolescents were **orphans and came from child-headed families** who did not receive any financial support. This made it hard for adolescents to acquire the ability to pay for transportation to the center.

'Some of the adolescents are orphans so sometimes, they tell you their situation and you are so astonished that you do not know what to say and do' HCP 5

Some adolescents confided that they were not in the Teen Club because they could not afford to come monthly for ART refills. Some healthcare providers indicated '*...WHO stopped giving them money for coming to the Teen Club whereby, they say the children would stop taking the pills once the organization leave since the parents end up saying these are government's children. Now the parents are responsible for giving their children bus fare then PEPFAR meet us with food.*', HCP 3 (only adolescents classified as OVCs were given financial assistance).

#### **4.2.5. Appropriateness and Ability to Engage in HIV Care**

The appropriateness of HIV care was mainly facilitated through the coordination and continuity of HIV care and the technical and interpersonal quality of healthcare providers.

**Sending Reminders and Calling Adolescents for Refill Dates:** The healthcare providers stated that the health center coordinated and ensured the continuity of HIV care by sending reminders (Short Message Service (SMS)) 24 hours and calling 48 hours before the actual refill dates to ensure continuity of care. This healthcare provider said: '*So, when we have appointed them before the date, we call them to remind them that your day to come and get your pills has come so remember to come*' HCP 9

Adolescents who had been identified as problematic and noncompliant with treatment and appointments were then called by expert clients and peer navigators. This

was coordinated through support from non-governmental international organizations.

Some of the participants indicated:

‘Here they send me a reminder when to come to the hospital.’ ALHIV 7

‘With the help of George our partner, you see Georgetown has provided us with a cell phone and airtime to call because we normally take the details of the patients.’ HCP2

‘So, when we have appointed them before the date, we call them to remind them that your day to come and get your pills has come so remember to come.’ HCP 9

**Coordination and Continuity of HIV Care - Short Lines:** As part of the coordination of the HIV services, the appropriateness of HIV care was facilitated through short lines. The healthcare providers reported that the adolescents were able to access any HIV-related services that may not be in the same consultation room on time. Healthcare providers noted that most adolescents did not like standing in a line let alone long lines, therefore, the short lines were appropriate. Some of the participants said:

‘The lines are not long here, and it is not slow.’ ALHIV 1

‘We only have short lines here not like the other pharmacy because the people here just come for one thing.’ HCP 12

‘... they do not like queuing for too long, they feel like going back when they are long lines particularly males at least the females they are trying.’ HCP 4

**Coordinated Monitoring of ART Adherence and Immune Monitoring:** Continuity of HIV care and engagement of adolescents in HIV care was ensured by coordinated monitoring of ART adherence (pill count) and immune monitoring (CD4 count and viral load). The pill count was done monthly for those in the Teen Club or whenever the adolescents came for an ART refill. The viral load monitoring was done twice annually for adolescents who were virally suppressed. For adolescents who were not virally suppressed it was every three months until a virally suppressed result was obtained. This HCP indicated:

‘We do a pill count, and we talk about defaulting when we identify some who have defaulted if the pill count, we are not satisfied we do talk about it’ HCP 11

The healthcare providers congratulated and told the adolescents to keep up if they were taking their drugs well, or if they were virally suppressed. It was reported that congratulating the adolescents motivated them to continue with the treatment. Some participants indicated:

‘When we count the pills, they also tell me if I’ve been taking my pills the way I’m supposed to, and they help me to continue’ ALHIV 1

**Mentoring and Empowering Adolescents:** Mentoring and empowerment offered by mentor mothers (M2M) and peer navigators enhanced the engagement in HIV care. Mentor mothers are women living with HIV who work as community health workers in health facilities and communities across several African countries. The M2M collaborates with healthcare providers and other educators to encourage, educate, and empower HIV-positive pregnant adolescents and new mothers about their health and their babies. Some HCPs indicated:

‘The mother 2 mothers, we call them M2M, they teach, work with us, mentor these young mothers with children as they have HIV.’, HCP8.

Peer navigators on the other hand were trained people living with HIV or not, who counseled ALHIV and encouraged engagement and retention in care and support services. The peer navigators helped the adolescents to navigate the intimidating world of HIV treatment. These peer mentors and educators had technical interpersonal qualities which helped the adolescents to continue in care and to bond well with these healthcare workers. Some HCPs indicated:

‘As the word suggests, the peer navigators act as friends who help the adolescents to navigate the hospital, especially for HIV, act as treatment

supporters and teach the adolescents how to live with HIV and treatment.’, HCP 4.

The health center reported that this was further strengthened by the availability of a youth-friendly nurse. The healthcare providers said *‘We have one trained youth-friendly nurse that helps our young ones a lot. This nurse is friendly and talks in the language of the youth. They like that and come for services that are like that.’*, HCP 9.

*‘When I have a teenager, I give myself time to talk about adherence, advice, when does he take the medication, and any challenges.’* HCP 5

The healthcare providers stated that they had adopted **a supermarket approach to HIV care**. The supermarket approach in HIV care was defined as accessing all needed HIV services in one consultation room instead of going to different rooms and queueing more than once. Some HCPs indicated:

‘There is something called the supermarket approach whereby we try to give you all the services that you need in one office instead of queuing here and there. That is why we have the ART dispensed at the PHU for the children, their mothers, and those expecting.’ HCP12.

Healthcare providers observed that the adolescents’ ability to engage with HIV care was enhanced by the empowerment, information, and guidance the adolescents got from their mentors and healthcare providers. This sentiment was echoed by both the adolescents and the healthcare providers. The use of healthcare workers living with HIV was reported to have further galvanized the adolescents’ ability to engage with HIV care. Some participants indicated:

‘We do referrals to ECs who have been on medication for a long time at a younger age to motivate and use themselves as references to the children.’ HCP 11.

‘... having expert clients really helps a lot because they act as role models for these children which help them to continue with their treatment.’ HCP 12.

‘... they tell me that they also have HIV, but see they are old, and they are working, which means I can also be like them one day.’ ALHIV 1

Despite all the efforts, there were some barriers to the appropriateness of HIV care and the adolescents' ability to engage in HIV care.

More staff is needed to support ALHIV. One adolescent-friendly HIV service healthcare provider is not enough. This inadequacy made it difficult for the adolescents to remain and be engaged in care.

'Youth-friendly services are not adequately offered in as much as we are trying... we have some kids who are still afraid of coming here, and adolescents that are afraid to come hence I feel like we are not giving them the youth-friendly services accordingly' HCP 6

**Lack of Training in Working with ALHIV:** In as much as some healthcare providers had the technical and interpersonal quality of how to work with ALHIV, the majority lacked that. The healthcare providers reported that they were not trained nor prepared to work with ALHIV. All healthcare providers stated that training or preparation on how to deal with adolescents living with HIV could be helpful. Some participants indicated:

'Some in the hospital just say it is those children who take... I do not know how to explain to you but some not good.' ALHIV 5

'Oh, yeah, some people when they are here, it's like they don't know how to talk to talk to children.' HCP 1

'... training can benefit me; I can understand the adolescents better.' HCP 11

**Hopelessness and lack of motivation:** The ability to engage with HIV care was impeded in adolescents who were hopeless and who in turn lacked motivation to continue seeking and engaging in HIV care.

Some healthcare providers observed that adolescents who were hopeless stopped taking HIV treatment and engaging in other HIV care with the hope of dying. Some healthcare providers said:

‘Some of the adolescents who have suicidal thoughts stop the treatment with the hope of dying.’ HCP 11

Additionally, the healthcare workers reported that some of the adolescents lacked the motivation to continue with HIV treatment and come to the health center. Some of the adolescents asserted that they sometimes felt demotivated and too lazy to come to the health center. They rationalized that they started the treatment when they were very young and had been coming to the center. Some of the adolescents were reported to have disengaged from HIV care. Some participants indicated:

‘So, they get tired of taking the drugs and not come... they feel demotivated to continue with treatment and coming here.’ HCP 10.

‘... sometimes I'm lazy to come and not come ... ALHIV 13

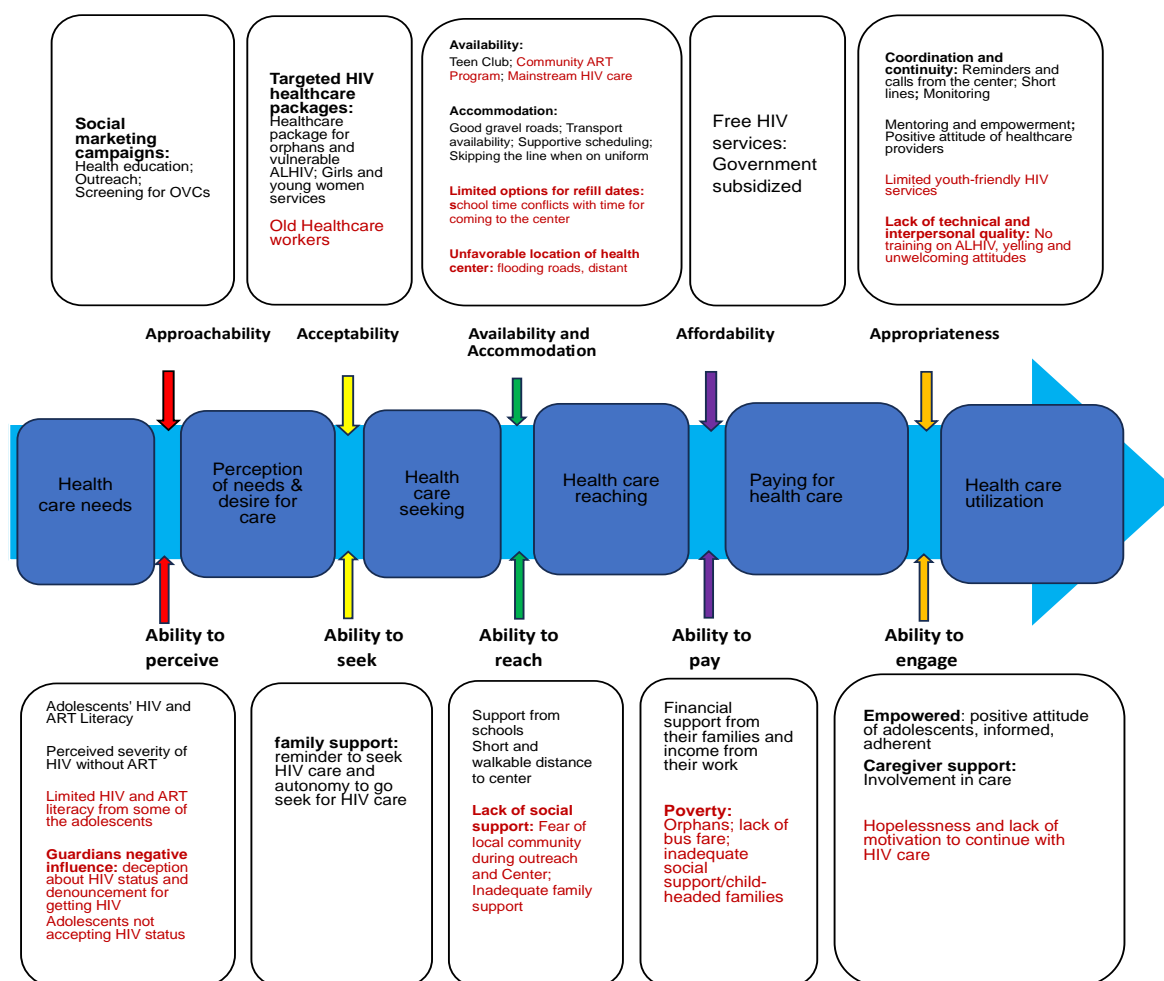


Figure 3. Summary Figure of Findings based on Levesque's Conceptual Framework of Health Care Access

#### 4.2.6. Recommendations from Participants for each HIV Service Access Issue

Both the healthcare providers and adolescents had recommendations that needed to be considered. Each HIV service access issue that was reported by the participants had a recommendation on how the identified issues could be addressed.

**Recommendation 1:** There is a need to continue educating the adolescents, their guardians/guardians, and communities about HIV services, ART, HIV disclosure



techniques, the importance of family support to adolescents, what it means to live with HIV, and the importance of ART compliance.

The healthcare providers recommended an increase in health education and marketing of HIV services to adolescents. They further stated that adolescents should be mentored to understand what it means to live with HIV. The healthcare workers recommended that the healthcare system should use more youthful peer educators and mentors because they share the same language as adolescents. Moreover, the HCPs asserted that would greatly help the adolescents to be empowered because the mentors served as their role models. Some healthcare providers said:

‘We need to continue to educate these people about their lives and what it means to them to be HIV positive HCP 1’

‘It should not be a once of thing but discuss it every day so that they can know it is a danger to stop taking the pills’ HCP 3

Most healthcare providers observed that there was a need for continued and improved education on HIV disclosure to the adolescents’ guardians and the public to harness support for adolescents. This was thought to reduce the stigma and unfounded judgment of adolescents living with HIV. Moreover, some HCPs asserted that having community pieces of training for all community members, not only those taking care of ALHIV would garner support for and understanding of ALHIV. They suggested that the communities could be taught about HIV, ART, the importance of supporting ALHIV, and disclosure techniques. This would reduce the number of adults asking adolescents about their HIV status when they find them at ART Clinics. Again, the training of guardians on HIV disclosure would reduce the number of adolescents on ART who did not know that they were HIV positive. Some HCPs indicated:

*'if the opportunity to educate can reach all people such that almost all of us understand HIV as a disease that can be acquired not only through unprotected sex but a sickness that can be acquired by any person.'* HCP 4

*'educating the community could be helpful because they can help support and make it easier for the children to come'* HCP 11

**Recommendation 2:** There is a need to offer supportive scheduling and widen the number of operating days or hours for adolescents because school time conflicts with that of the healthcare system.

Both the adolescents and healthcare providers recommended an increase in the number of days or operational hours dedicated to the youth such that all the youth could fully benefit from HIV services. It was observed that most of the adolescents spend their time at school or university thus making it harder for them to come to the center. The adolescents stated that there was a need for more than one Saturday for Teen Club activities in a month. Some healthcare providers recommended that their colleagues should have a range of dates for the adolescents to choose from not to impose their dates on the adolescents. Some participants indicated:

*'but having many Saturdays will be good to choose from'* ALHIV 13

*'if we can include the weekends as working days'* HCP 2

**Recommendation 3:** There is a need to change the location of the ART Clinic from the gate and construction of tall bridges in some communities.

The adolescents stated that there was a need to change the ART Clinic from the gate where everybody passes by. They mourned that the location of the health facility offered them no privacy and confidentiality. These adolescents indicated:

‘the hospital is close to where everyone sees us’ ALHIV 9

‘The house was not supposed to be at the gate’ ALHIV 8

Some of the adolescents stated that there was a need for tall bridges in their communities because they flooded quickly and easily during the rainy season. The bridges were reported to be too short which caused water to run over the bridges when it rained. This adolescent indicated:

‘Too much rain sometimes makes us not to be able to come because we cannot cross the rivers when they are full... Long bridges for the water to not touch the bridge’ ALHIV 10

**Recommendation 4:** There is a need for expansion of Outreach HIV Services that are adolescents friendly.

The healthcare providers stated that there was a need for an expansion of outreach HIV services because some patients come very far and may not have the resources to reach the center. Again, some healthcare providers felt like some adolescents at schools far from the healthcare center could be missing life-saving HIV services. Some HCPs indicated:

‘I feel like we are not reaching out enough for now... I feel like if we could go to the schools where they spend most of their time or probably once in a while’ HCP 6

‘just an adolescent and youth clinic with all the services not basing it on HIV or health condition’ HCP 12

**Recommendation 5:** There is a need for adolescent-friendly HIV services and to create safe spaces for adolescents.

Most of the healthcare providers mourned the lack of youth-friendly HIV services. Therefore, they recommended an increase in youth-friendly services to improve access and utilization of HIV services by adolescents and the youth. Some HCPs said:

‘if it was to happen for them to be open and assure them that their secrets will be held in confidence that person find themselves living better’ HCP 1

‘you need to make them feel part of you in what you are doing and then they will come close, and they will involve you’ HCP 11

There was a recommendation for creating adolescents’ safe spaces. This was echoed by most healthcare providers. The healthcare providers defined adolescent safe spaces as places where adolescents can share their views, and experiences, and explore solutions without fear of judgment or disrespect. Some HCPs said:

‘We really have to work on creating safe spaces for adolescents whereby nobody cares why you are in the hospital, what you are doing, and why you are here’ HCP 10

**Recommendation 6:** There is a need for training and preparation of healthcare providers on how to work with adolescents living with HIV.

The healthcare workers mourned the lack of training or preparation on how to work with adolescents living with HIV despite the overt need for such training. They stated they needed to be trained to be at par with the demands of caring for adolescents, especially those living with HIV. Some HCPs said:

‘Having education to us about the children we are caring for we can then maybe all welcome them nice and act like them in a good way’ HCP 3

‘We need the training so that we can be able to help the adolescents in each corner and service point of the hospital’ HCP 10

## CHAPTER 5

### DISCUSSION OF STUDY FINDINGS

This chapter presents the summary of the findings, interpretation of findings, limitations of the study, and recommendations for future research based on the data analyzed in the previous chapter. The purpose of this qualitative study was to explore factors influencing access to HIV healthcare services among adolescents living with HIV in an HIV-designated healthcare center in Eswatini using the Lévesque's conceptual framework of access to healthcare.

#### **5.1. Summary of Findings**

This qualitative study explored HIV service access issues experienced by adolescents living with HIV as they utilize HIV services in an HIV-designated healthcare center in Eswatini. The range of facilitators and barriers to access to HIV services, from both the adolescents and health system/healthcare providers included health literacy among adolescents and their parents, social awareness campaigns, HIV healthcare packages targeting population groups, age gap between ALHIV and HCPs, yelling at ALHIV, family support, Teen Club, mainstream HIV care, and the Community ART Program, geographic location of health center, accommodation of adolescents by HCPs, schools, subsidized HIV services, poverty among adolescents, reminders to adolescents, monitoring of adolescents on HIV care, training HCPs on working with ALHIV, and hopelessness.

While it seems that the health system is doing its level best to mitigate the barriers to HIV service utilization and enhance the facilitators, but the challenges are still

impeding the adolescents' abilities to perceive the need for HIV care, seek HIV care, reach HIV care, and finally engage in sustained utilization of HIV services. Overall, the HIV services seem not to be evolving with the ever-changing HIV needs of adolescents living with HIV.

It is important to note, that in this study we captured adolescent participants who were regular users of services. Likely, their standpoint is more favorable to HIV services than the remaining community of ALHIVs. However, the triangulation with the health care providers' perspectives covered the more comprehensive standpoint, which is for the community at large not only the current users.

The following discussion will focus on salient issues that emerged as challenges for the service users for each domain. We will provide a brief summary of the findings, followed by literature that echo, expand, or oppose our findings, and finally, suggestions to mitigate those challenges in order to improve access.

## **5.2. Interpretation of Findings**

### ***5.2.1. Approachability of HIV Services and the Ability to Perceive the Need for HIV Care***

The study findings reveal that *adequate health literacy and perceived severity of HIV without treatment* played a major role in initiating the ability to perceive the need for HIV care. This is consistent with a body of knowledge that adequate health literacy about HIV, ART, and available HIV service options in the health center made the adolescents perceive the need for HIV care (Mgbako et al., 2022). Mgbako et al. (2022) conducted a systematic review of factors critical for HIV health literacy, ART adherence, and retention in HIV care. According to Mgbako et al. (2022), people with low health

literacy levels miss more than three times as many HIV follow-up appointments as people with higher health literacy levels. Findings from both Mgbako et al. (2022) and Palumbo (2015) assert that poor health literacy is a social barrier to accessing HIV healthcare services among patients living with HIV. Palumbo (2015) further reveals that poor health literacy is associated with a lower level of disease risk perception and less likely to follow HCPs' instructions. Health literacy is also a prerequisite to improving the utilization of HIV services among HIV-infected individuals (Rodkjaer et al., 2023; Wawrzyniak et al., 2013.)

The logic model connecting health literacy and perceived need can be interpreted in the light of the well-established health belief model (HBM). HBM asserts that an individual's perceived need to adopt a certain behavior is determined by the perceived benefits of acting on this behavior. For HIV adolescents, the behavior to seek, reach, and utilize HIV care is determined by their perception of the perceived advantages of receiving care (Jones et al., 2015; Khumsaen & Stephenson, 2017). Conversely, limited health literacy hindered the adolescents' ability to perceive the need for HIV care. Limited health literacy impedes adolescents' ability to recognize the need to utilize HIV services. This also affected the health belief about HIV without treatment. Limited health literacy has been shown to contribute to poor HIV service utilization (Rodkjaer et al., 2023).

To enhance the approachability of HIV healthcare services and improve the ability to perceive the need for care, the health system should intensify social awareness campaigns. Tailored interventions should be aimed at enhancing the health literacy of adolescents to improve their ability to perceive the need for HIV care.

Another important factor identified in this study is *the deception from guardians*, which greatly contributed to the lack of insight among adolescents about the need for HIV

care. Without the adolescents knowing that they have a chronic condition that needs treatment, how can they perceive the need for HIV care nor recognize the severity of HIV without treatment?

Our findings are however consistent with other studies in Eswatini, which found that parents do not tell their children the truth about their HIV status (Ahmed et al., 2022; Dlamini & Matlakala, 2020). Non-disclosure of HIV status has been identified as one of the potential barriers to optimum utilization of HIV services, especially in adolescents (Hayfron-Benjamin et al., 2018; Khangale et al., 2022). HIV disclosure serves as the first step to achieving the global 95/95/95 goal. Disclosure of HIV status to adolescents is essential for both personal health maintenance and HIV prevention within the larger population (Appiah et al., 2021).

Despite the emerging scientific evidence of the benefits of HIV disclosure, there appears to be no available guidelines for teaching guardians about HIV disclosure to adolescents. It is, therefore, essential to train HCPs to support guardians and adolescents through the disclosure process to ensure that guardians realize the benefits of disclosure (Madiba & Diko, 2020). There is a need for HCPs to prepare, support, and empower guardians to develop appropriate responses to adolescents' questions and to understand the implications of deception on future full disclosure and adolescents' acceptance of their HIV status (Molokwane & Madiba, 2021).

### ***5.2.2. Acceptability and Ability to Seek HIV Care***

HIV healthcare packages targeting population groups appeared to be highly accepted by all adolescents and improved their ability to seek HIV care. These results confirm the existing evidence that people-centered HIV services, that address challenges



in accessing services improve the acceptability of HIV care (Abboah-Offei et al., 2020; Burton et al., 2017; Chinyandura et al., 2022; WHO, 2016). The health center improved the adolescents' ability to seek HIV care through adolescent-centered HIV services, such as OVC and AGYW. There is concordance in the study findings with that of Bristowe et al. (2019) in that a people-centered approach enables professionals to deliver responsive HIV care to the specific needs of the individuals (Bristowe et al., 2019). Hence, cash assistance, reducing queuing, and other measures taken enhanced the ability of adolescents to seek care. It is important to adapt and adopt this tailored HIV-care program design to specific patient population groups and service delivery in other contexts.

The family support facilitated through reminders to seek HIV care and autonomy to seek HIV care sharpened the adolescents' ability to seek HIV care. Having families understand the vital role they play in adolescents' health and well-being as they promote the utilization of HIV services is important. Most adolescents are uniquely dependent on guardians to access HIV services and treatment. Therefore, the family's support is crucial. The results show that family support is associated with optimal access to HIV services (Khumalo et al., 2020). Without family support, adolescents may be denied autonomy to seek HIV care. Consistent with a body of knowledge, families should be educated to increase awareness of the importance of supporting adolescents living with HIV (Winskell et al., 2016).

A huge age gap between healthcare providers and beneficiaries hindered adolescents from seeking HIV care. Our findings are consistent with other studies, healthcare providers of advanced years sometimes exercise their authority by behaving as a parent figure which negatively influences patient participation in HIV care (Dapaah,

2016). Young healthcare providers who do not have a huge age gap from adolescents could be used to improve adolescents' HIV care-seeking behavior.

As with previous studies, frequent yelling at adolescents and unwelcoming healthcare providers' attitudes towards adolescents curtail their ability to seek HIV care (Pantelic et al., 2020). In a study conducted by Pantelic et al. (2020) adolescents living with HIV also reported frequent instances of healthcare providers shouting at them, which they experienced as discrimination. Pantelic et al. (2020) found that adolescents living with HIV frequently experience shouting from healthcare providers, which they perceive as discrimination. A common type of discrimination experienced by ALHIV is being shouted at by healthcare providers (Pantelic et al., 2020). The treatment of ALHIV by the HCPs negatively impacted access to HIV services as some adolescents did not return to seek HIV care again (St Clair-Sullivan et al., 2019). Creating a code of conduct committee to educate all healthcare providers about disrespectful behavior, define the behavior, list examples, and develop an action plan that identifies disrespectful behavior, addresses it, and measures institutional success (Grissinger, 2017). This could contribute to a reduction in disrespectful behavior within the healthcare system and improve access to HIV services.

### ***5.2.3. Availability and Accommodation and Ability to Reach HIV Care***

The study findings reveal that the health center did its best to avail HIV services through mainstream HIV care, the Community ART Program, and the Teen Club. Unfortunately, the adolescents disliked *mainstream HIV care* thus hindering their ability to reach and use HIV care. Consistent with scientific evidence, the results show that traditional approaches to HIV care are poorly reached and utilized by adolescents living

with HIV hence hindering the achievement of global HIV targets (Maskew et al., 2022). It is high time that the health system recognized that, the one-size-fits-all approach to HIV service delivery is unlikely to result in sustainable improvements in HIV service utilization. Maskew et al. (2022) state that differentiated models of HIV care could offer simplified and patient-centered HIV care options tailored to each stage of the patient care journey. Consistent with previous studies, adolescent HIV services delivered in community-based groups with peer navigators have the potential to increase the reach of HIV services (Maskew et al., 2022).

Previous research has found that adolescents benefited from ***Community ART Distribution Models*** through reduced transport costs, convenience of accessing HIV care and treatment, and social support (Miyingo et al., 2023). Conversely, the results of this study demonstrate that the adolescents did not benefit from the Community ART Distribution Models and were not socially supported. The Community ART Distribution Models appeared to be provided as in the health center except that it was given in a community. However, the study findings concur with that of Miyingo et al. (2023) in that the challenges associated with these models are a lack of confidentiality and privacy and perceived stigma (Miyingo et al., 2023). Similarly, the participants in this study did not benefit from such a model due to fear of accidental disclosure and stigma. It is important to highlight that the adolescents did not like/rely on mobile or outreach HIV services despite the region's great reliance on and investment in outreach HIV services (PEPFAR, 2021). While it has several advantages mitigating the challenges reaching the clinic, the Ministry of Health and implementing partners need to find a mechanism for improving confidentiality and privacy and addressing perceived stigma to improve HIV service delivery for adolescents. Perhaps one way of improving acceptance is to engage

adolescents in the pre-planning of HIV services for the HIV services to be responsive and appropriate for their HIV service needs.

The results show that **Teen Clubs** facilitated the adolescents' ability to reach HIV care. The study results build on existing evidence on the effectiveness of Teen Clubs in improving adolescents' ability to reach and use HIV care. Teen Club improved utilization and retention in HIV care among adolescents (Munyayi & van Wyk, 2020). A retrospective cohort study conducted by Trapence et al. (2023) in Malawi also showed that Teen Clubs improved the usage of HIV care and retention in care. An impact evaluation of the Teen Club program in Eswatini revealed that it improves the utilization of HIV care and ultimately retention and good health outcomes (UNICEF, 2019). The importance of support groups for adolescents living with HIV is well established in increasing adherence and retention in HIV care and treatment (Charles et al., 2022; Mazambara et al., 2022). Popular literature reports that Teen Clubs are not integrated into existing healthcare services (Ministry of Health et al., 2018), but to the contrary, the Teen Club in the health center was integrated into existing healthcare services. This was evident by the fact that the Teen Club was managed only by local health center staff and health records were housed with other health records. Moreover, the use of a supermarket approach corroborates this finding. Adolescents who need other healthcare services like contraceptives were provided. The integration helps the adolescents to be able to access other HIV services on any day other than the day dedicated to Teen Club activities. Furthermore, even for adolescents who may miss the day of the Teen Club, the health center invites them to come on any other day as early as possible.

Despite the well-documented effectiveness of Teen Club programs in improving HIV service utilization, it is not decentralized in Eswatini. Having the Teen Club only in

high-volume areas deprives some of the adolescents in desperate need of such peer-to-peer support groups. Again, it means that the adolescents have no choice but to use non-fully accessible HIV services which culminates in unsustainable HIV service utilization. Based on the literature, adolescents who are from disadvantaged backgrounds are the ones that are hardly hit by HIV and at the same time may not be able to utilize the HIV services. (CDC, 2019; Kidman & Anglewicz, 2016). It, therefore, implies that some of the adolescents in Eswatini could be missing the indispensable facilitator of the adolescents' ability to reach and use HIV care.

The study findings show that some adolescents were able to reach HIV care as a result of having good gravel roads and tall bridges. Conversely, adolescents who came from communities with bad gravel roads and short bridges were unable to reach the health center during the rainy season due to flooding. As a result of the slippery roads and water moving over bridges during the rainy season, some of the adolescents had interrupted utilization of HIV services. The study findings concur with that of Kadio et al. (2023) in that poor accessibility of roads during the rainy season, interrupted access to ART clinics at certain times during the year in some settings. Moreover, in the rainy season, it is even more difficult for adolescents to access the area where the hospital is located (Dorcélus et al., 2021). Moreover, the health center is unable to provide outreach HIV services in some settings during the rainy season. Given this seasonality trend, the Swazi government and its stakeholders must provide a specific plan for overcoming the rainy season effect. Kadio et al. (2023) suggest that conditions related to climatic factors undermine access to HIV treatment sites and should be further evaluated to mitigate such climatic factors.

The results show that the standalone ART Clinic and being by the gate at the health center did not accommodate the adolescents' privacy. Consistent with the

literature, most adolescents prefer to access HIV services in privacy to avoid being identified by relatives or acquaintances (Dapaah & Senah, 2016). As with previous findings, privacy concerns lead to missed doses, refills, or appointments and ultimately suboptimal use of HIV services (Bwanika et al., 2022; NIH, 2023; St Clair-Sullivan et al., 2019). Therefore, when HIV services are devoid of privacy the adolescents shun them which in turn curtails their ability to reach HIV care. The location of the ART Clinic deprives the ALHIV of their right to privacy as they reach for HIV care (Bwanika et al., 2022). The concern is that the exterior appearance and labeling of the clinic identify that the structure is being used for HIV care provision only. It is therefore important that the reason for the physical presence of the adolescents in the health facility is not known by other people. The health system should not forget the interest and welfare of adolescents who are the ultimate beneficiaries of HIV healthcare services. Integration or isolation of the HIV services must ensure that adolescents are guaranteed privacy in the use of HIV services to avoid identification in the health care setting and prevent stigmatization. This is likely to encourage the adolescents to continue accessing HIV services and, also motivate potential beneficiaries to use HIV services (Dapaah & Senah, 2016).

The findings reveal that schools played a major role in the adolescents' ability to reach for HIV care as the schools allowed them to go to the ART Clinic. This allowed students to access HIV services during school time despite the conflicting schedules. Conversely, some of the students were unable to reach HIV care due to limited support from their schools. Furthermore, this has also been attributed to structural barriers including HIV services not being youth-friendly with opening hours conflicting with school time (St Clair-Sullivan et al., 2019). Consistent with a body of knowledge, there is a clash between school activities, and scheduled clinic appointments for ART refills

and other HIV services (Madiba & Josiah, 2019). There is a need for school support to accommodate the student's need for HIV care while adhering to privacy and confidentiality protocols (Barker et al., 2019; Mutumba et al., 2022). On the other hand, the results indicate that the health center can play a key role through supportive scheduling. This was evident with some healthcare providers scheduling the adolescents very early in the morning or after school. As with previous study findings, there was support for adolescent clinics being scheduled after school (Woollett et al., 2021). Woollett et al. (2021) stated that a clinical appointment could be set for the adolescents by timetable or maybe have them attend when they come back from school, so that they do not miss out on schooling. Healthcare providers need to involve adolescents in their HIV to understand their school timetable and examination dates. It helps adolescents to engage in HIV care because they are involved in the decision-making during appointments. Based on the findings, it is high time that healthcare providers do not impose their dates on the adolescents, but rather discuss the appointment with adolescents. By so doing, it will help adolescents to utilize HIV services.

The findings reveal that all adolescents in school uniform were allowed to skip the line and have their need for HIV services fast-tracked. Previous studies have found that adolescents in uniform got shouted at when they asked to be helped early as they came in the morning to go back to school. The healthcare providers said that the adolescents in uniform should be in the line instead of helping them quickly in order to go back to school (St Clair-Sullivan et al., 2019). On the contrary, this study demonstrates that healthcare providers helped adolescents in uniform to skip the line and sometimes booked them early in the morning so that the adolescents would return to school early. This helped the adolescents to access HIV care timely and motivated them to come back

again. Standardizing the skipping of lines offered to adolescents when in uniform could help facilitate access to HIV services and ensure that adolescents do not miss school when coming for HIV care.

The study findings reveal that adolescents who lived within a short and walkable distance of the health center were able to reach HIV care easily. The walkable distance further enhanced the adolescents' ability to reach HIV services by removing transportation barriers. Consistent with the literature, distance to HIV health facilities is an important contextual factor influencing access to HIV services (Sanga et al., 2019). Adolescents from lower socioeconomic status are spared from higher transport costs which curtail their abilities to reach and pay for HIV care (Ahmed et al., 2022). Therefore, decentralization of ART Clinics throughout the country could improve HIV service utilization by adolescents living with HIV.

#### ***5.2.4. Affordability and Ability to Pay for HIV Care***

Consistent with the literature, the results show that all HIV services are subsidized and made free by the Swazi government to all individuals (Becker et al., 2020; Steinert et al., 2021). This makes HIV services financially accessible to adolescents which encourages them to use the HIV services. Despite HIV services being free to all HIV-infected individuals for decades, some adolescents still cannot pay for indirect costs to access HIV services. It comes as no surprise, as an estimated 59 percent of the population lives below the poverty line, with 29 percent of the population living in extreme poverty (World Bank, 2020). The findings reveal that some of the adolescents who are devoid of the ability to pay for HIV care are orphans and others come from child-headed families. Consistent with findings from previous studies, these adolescents are unable to pay for



high expenses for transport to and from the health center (Sanga et al., 2019; Steinert et al., 2021). The socio-economic status of adolescents who are orphans renders HIV services inaccessible and inequitable. The Swazi Government and its implementing partners should find sustainable solutions to help such disadvantaged adolescents if the country is to realize the HIV global targets by 2030.

#### ***5.2.5. Appropriateness and Ability to Engage in HIV Care***

The study findings reveal that sending reminders and calling adolescents for ART refill dates helped the adolescents to engage in HIV care. Consistent with the literature, the reminders to the adolescents improve utilization of HIV services when compared to standard care where the adolescents were not reminded (Abdulrahman et al., 2017). The monthly reminders for most adolescents probably enabled the establishment of routines. The calling of some beneficiaries and sending text messages improve service access and the adolescents' ability to engage with HIV care. The findings further reveal that the adolescents were happy to receive appointment reminders and calls because they come after a month or two. The reminders also had positive impacts on ART adherence as the adolescents accessed ART and got other supportive HIV services.

The results indicate that coordinated monitoring of ART adherence and immune monitoring made the HIV services appropriate because the adolescents viewed them as the reward and revelation of their good work in the utilization of HIV services. It kind of motivated them to continue in HIV care knowing that one day the healthcare providers will congratulate them for an undetected viral load or viral suppression. Moreover, monitoring helps in identifying the reasons for suboptimal clinical outcomes and applying the appropriate interventions (Jacob et al., 2017) which improve access to HIV care.

Ongoing monitoring of HIV treatment that promotes HIV service utilization is key to ending the HIV epidemic (Jennings et al., 2023). The poor utilization of HIV services by adolescents has increasingly been recognized as a pressing public health challenge, particularly in sub-Saharan Africa. Regular clinic visits have been established as an effective proxy for HIV services access and treatment adherence in some sub-Saharan countries (Spreckelsen et al., 2022).

The results reveal that trained healthcare workers on how to work with adolescents living with HIV provide responsive and appropriate HIV care. This is very important as it empowers adolescents and promotes engagement in HIV care. The findings speak to the growing literature on the need for healthcare provider preparation or training about adolescents living with HIV. Consistent with the literature, caring for adolescents living with HIV can be overwhelming due to their unique needs (Hayfron-Benjamin et al., 2020). Therefore, scaling of training of healthcare providers on working with adolescents living with HIV could help empower more adolescents. Moreover, they reveal that the use of trained peer educators (expert clients, mother-to-mothers, and peer navigators) greatly helps in mentoring and empowering adolescents. This helps the adolescents to model good behavior and use peer educators as their role models thus promoting engagement with HIV services (Hayfron-Benjamin et al., 2020). As a result, the trained HCPs and HCPs with positive interpersonal skills help to empower the adolescents (positive attitude of adolescents, informed, adherent).

Targeted training on ALHIV care and psychosocial support could be effective in increasing HCPs' knowledge, skills, and confidence in working with ALHIV. Addressing the healthcare system/facility-related gaps serves as an impetus for improved access to HIV services (Hayfron-Benjamin et al., 2020). The WHO advocates for specific

competency-based training for all HCPs involved with ALHIV care to enable them to provide high-standard HIV services and supportive services to them and their families (WHO, 2011). The study findings have important implications for developing effective educational interventions targeting healthcare providers working with adolescents living with HIV.

On the other hand, the findings reveal that most healthcare providers are not trained or prepared on how to work with ALHIV thus some of the HCPs have stigmatizing and unsupportive practices. This is consistent with a body of knowledge where there is a limited number of HCPs who have adequate knowledge and skills to comfortably provide developmentally appropriate HIV care and related services (Chem et al., 2022; Hayfron-Benjamin et al., 2020; Karman et al., 2020). As in previous studies, health workers noted that adolescent-friendly HIV services were either non-existent or poorly executed in HIV treatment facilities (Chem et al., 2022; Hayfron-Benjamin et al., 2020; Karman et al., 2020). The related HIV services could be disclosure, provision of ongoing supportive counseling, and addressing the care and treatment adherence issues. The situation is particularly so in sub-Saharan Africa, Eswatini inclusive, where the number of HCPs trained in youth-friendly HIV services is limited. Training coverage for adolescent HIV care remains suboptimal, despite the overt need for trained HCPs (Hayfron-Benjamin et al., 2020; Karman et al., 2020). The time is ripe to implement the WHO competency-based training for all HCPs involved with ALHIV. This would address the poor and unstained utilization of HIV services by adolescents (Hayfron-Benjamin et al., 2020). Trained and adolescents-friendly could be a magnet for the adolescents using the HIV services. The lack of HCP training is a barrier to implementing youth-friendly services (Karman et al., 2020). The 95-95-95 targets will only be achieved with trained HCPs and

zero discrimination, including within healthcare settings. To ensure health workers are equipped to deliver appropriate HIV services, training and sensitization are required. Mutambo and Hlongwana (2019) assert that training, mentoring, and providing healthcare workers with guidelines on how to provide adolescents-focused HIV care have the potential to address the majority of the barriers to HIV service utilization (Mutambo & Hlongwana, 2019).

The study revealed that adolescents who came from supportive guardians had a sustained ability to engage in HIV care. Consistent with the literature, guardians are integral to the utilization of HIV services and retention in care for ALHIV (Enane et al., 2020). Adolescents with limited guardian support due to orphanhood, guardian illness, severe poverty, family denouncement, and family conflicts have the greatest challenges in accessing HIV services and staying in care. Therefore, such adolescents suboptimally use HIV services and appear to be at risk of disengagement. Promoting access to HIV services for the most vulnerable adolescents requires guardian support to enhance engagement in HIV care (Enane et al., 2020). The study findings have important implications for developing effective psychosocial and educational interventions targeting adolescents living with HIV and their guardians to facilitate guardian support for ALHIV.

The study findings indicate that hopelessness caused some adolescents to disengage from HIV care. Consistent with the literature, some adolescents consider suicide by stopping taking their medications, or halting clinic attendance altogether as a result of being hopeless (Ahmed et al., 2022). There is a need to take advantage of the presence of peer educators and lay healthcare providers to help adolescents deal with such phases of the HIV care journey. Consistent with previous studies, the use of expert clients

who are of the same age as the adolescents helps to empower the adolescents and keep them in care (Ahmed et al., 2022). The adolescents model their HIV-positive life journey as that of the expert clients. These findings have implications for using more youthful expert clients in adolescent HIV care settings to improve adolescents' engagement in HIV care.

### **5.3. Strengths and Limitations of the Study**

The findings of this study have to be seen in light of some strengths and limitations of the study. The study used triangulation whereby adolescents and healthcare providers were sources of data, to increase the validity and credibility of the findings. The triangulation helps in overcoming the limitations of a single source and provides a more comprehensive and balanced understanding of the research topic. This is the first research to study the access issues to HIV services experienced by adolescents living with HIV in Eswatini. The study is a rich source of in-depth knowledge about the HIV service access issues experienced by adolescents in the rural Lubombo Region. The study was undertaken in the rural Lubombo region and therefore, the findings are not representative of all adolescents living with HIV in Eswatini. However, we believe the findings can be transferrable to other settings, similar to the Lubombo region (Nsibandze et al., 2021).

In terms of our sample participants, some of the adolescents might not have been mature and brave enough to discuss the issues that they face when accessing HIV services which appeared to be caused by the healthcare providers. However, we tried through probing and triangulation to provide a more comprehensive understanding of the situation, but we acknowledge there may be caveats.

The mere fact that our adolescent participants were actually current users of services is a major limitation. For logistical reasons, we were not able to reach the non-users and get their perspectives on what hinders them from using the services. The results perhaps will shed light on other issues not covered in this sample. However, the triangulation with the health care providers tried to shed light on issues not raised by adolescents but by the community at large.

#### **5.4. Future Research**

While these limitations have not impacted the primary outcome of the study, future work could seek to include additional controls in balancing out the participants based on the mode of HIV transmission and non-users of HIV services. This study could be used as a basis for future research in understanding HIV service access issues experienced by adolescents living with HIV.

Future research could include adolescents living with HIV who are non-users of HIV services to study HIV access issues they experience.

Further research on how training guardians, and HCPs on how to deal with ALHIV is needed to better understand how it affects access to HIV services by adolescents.

Further examination of how implementation sciences could be used to improve the design of ART clinics. Such research could contribute to improved appearance of clinics, privacy, and confidentiality of adolescents thus resulting in utilization of HIV services.

Further research could investigate how participatory approaches to HIV service planning can help improve HIV service utilization. Such an investigation could help in

designing HIV programs and services that are sensitive to the healthcare needs of adolescents.

Future studies could investigate the role the community could play in improving access to HIV services for ALHIV. Such a study could, craft interventions that equip the community to support the adolescents and not alienate them.

## **5.5. Conclusion**

In summary, this study explored factors influencing access to HIV healthcare services among adolescents living with HIV in an HIV-designated healthcare center in Eswatini using the Lévesque's conceptual framework of access to healthcare. Previous studies explored general experiences of ALHIV with a limited focus on access to HIV healthcare services, despite the documented poor access to HIV services in sub-Saharan Africa. This study illuminates the HIV service access issues that adolescents living with HIV in the rural Lubombo region experience, which curtail their ability to utilize HIV care. Utilization of HIV health services among ALHIV is still a major public health concern, thus understanding their HIV health-related needs is crucial for effective programming (Chem et al., 2022).

This study demonstrates that both adolescent factors and health system factors influence access to sustained HIV service utilization. Health literacy of adolescents and their guardians, social marketing campaigns of HIV services, HIV service affordability, geographic location of clinic, population-targeted HIV healthcare packages, healthcare providers' attitudes toward adolescents, model of HIV service delivery and preparation of HCPs on working with ALHIV all influence the utilization of HIV services by adolescents.

## **5.6. Recommendations**

There is a need to adapt social awareness marketing campaigns of HIV services to the context of the beneficiaries and their circumstance to be impactful. This would contribute to the health literacy of the population and understanding of the available HIV service options. This would further enhance the approachability of the health center for HIV services. It could also help guardians learn how to disclose and support their children living with HIV.

There is a need for the health system and its implementing partners to find sustainable financial solutions for adolescents living in poverty. This could contribute to HIV service equity as some of the adolescents can then afford to pay for public transport to the HIV clinic. If the country is to achieve sustained control of HIV infection, all adolescents living with HIV should have unimpeded access to HIV care.

There is a need to review the geographic location of HIV clinics because the clinics deprive adolescents of privacy due to their branding and standalone nature. Again, the improvement of the road infrastructure is vital to enable access to HIV services during the rainy season which sometimes causes the roads to be slippery and flooding.

There is a need to increase the breadth of the population-targeted HIV healthcare packages to all adolescents because they help promote access to HIV services.

There is a need to adopt a participatory approach when designing HIV programs/services in order for the programs/services to meet the HIV service needs of the beneficiaries and in turn for the beneficiaries to use them sustainably.

There is a need for preparation/training of HCPs on working with adolescents living with HIV as stated by the World Health Organization. This could improve the



competence of the healthcare providers on how to work with this unique and evolving population. This would in turn improve the provision of adolescents-friendly services.

## APPENDIX 1

### DATA COLLECTION INSTRUMENT FOR ALHIV: A SEMI-STRUCTURED TOPIC GUIDE

#### Ability to perceive

1. How important it is for you to receive ART?

#### Recommendations

For the challenge you have mentioned, in your own opinion how can it be solved (**IF ANY FOR EACH CHALLENGE**)?

#### Ability to seek

2. To what extent do you value ART?
3. To what extent does your family/community value ART?

#### Recommendations

For the challenge you have mentioned, in your own opinion how can it be solved (**IF ANY FOR EACH CHALLENGE**)?

#### Ability to reach

4. Can you tell me about things that make it easy for you to reach the center?
5. Can you tell me about things that make it difficult for you to reach the center?

#### Recommendations

For the challenge you have mentioned, in your own opinion how can it be solved (**IF ANY FOR EACH CHALLENGE**)?

#### Ability to pay

6. How do you afford to pay for the treatment?

#### Recommendations

For the challenge you have mentioned, in your own opinion how can it be solved (**IF ANY FOR EACH**)?

#### Ability to engage

7. What has helped you to keep taking your treatment?

#### Recommendations

For the challenge, you have mentioned, in your own opinion how can it be solved (**IF ANY FOR EACH**)?

## APPENDIX 2

### DATA COLLECTION INSTRUMENT FOR HEALTHCARE PROVIDERS: A SEMI-STRUCTURED TOPIC GUIDE

#### The approachability of healthcare

1. To what extent the center is spreading information about the importance of ART?
2. How does the center bring ART services to ALHIV who may have challenges reaching the center?
3. Can you describe circumstances in which the center or ART healthcare providers (HCPs) may have been unapproachable to ALHIV?

#### Recommendations

For the challenge you have mentioned, in your own opinion how can it be solved (**question to be asked after each mentioned challenge/issue**)?

#### Acceptability

4. Can you describe any preparation /training you got on how to deal with ALHIV to facilitate their access to HIV services?
5. How does the center advocate or support ALHIV?
6. In your opinion, how does the center/ HCP impede access to treatment for ALHIV?

#### Recommendations

For the challenge you have mentioned, in your own opinion how can it be solved?

#### Availability and accommodation

7. Can you provide your opinion on how the location of the center is facilitating the services?
8. Can you provide your opinion on how the operation of the center is facilitating or impeding the services?
9. Can you describe HIV services that target ALHIV in the center (e.g., adolescents-friendly services, days for ALHIV, etc.)
10. How do your appointment mechanisms accommodate students living with HIV who may be getting HIV treatment here?

#### Recommendations

For the challenge you have mentioned, in your own opinion how can it be solved?

#### Affordability

11. How does the center fund its HIV services?
12. In your opinion, how do the waiting times in the center facilitate access to HIV treatment?
13. In your opinion, how do the waiting times in the center impede access to HIV treatment?

#### Recommendations

For the challenge, you have mentioned, in your own opinion how can it be solved?

Appropriateness

14. How do you promote continuity of HIV care?
15. How do you involve the ALHIV in healthcare decision-making (e.g., changing drug regimens or months of monitoring, etc.)?
16. In your opinion, how does the center impede the continuity of care for ALHIV?

Recommendations

For the challenge you have mentioned, in your own opinion how can it be solved?

## APPENDIX 3

### CONSOLIDATED CRITERIA FOR REPORTING QUALITATIVE RESEARCH (COREQ) CHECKLIST

Topic	Item No.	Guide Questions/Description	Reported on Page No.
<b>Domain 1: Research team and reflexivity</b>			
Personal characteristics			
Interviewer	1	Which author/s conducted the interview or focus group?	30
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	30
Occupation	3	What was their occupation at the time of the study?	30
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	31
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	30
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons, and interests in the research topic	13
<b>Domain 2: Study design</b>			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study?	27
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	29
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	32
Sample size	12	How many participants were in the study?	33
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	28
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	27
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	25
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	31
Repeat interviews		Were repeat interviews carried out? If yes, how many?	

Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	32
Field notes	20	Were field notes made during and/or after the interview or focus group?	35
Duration	21	What was the duration of the interviews or focus group?	32
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or correction?	
<b>Domain 3: analysis and findings</b>			
Data analysis			
Number of data coders	24	How many data coders coded the data?	1
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	34
Software	27	What software, if applicable, was used to manage the data?	34
Participant checking	28	Did participants provide feedback on the findings?	
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	38 -56
Data and findings consistent	30	Was there consistency between the data presented and the findings?	64
Clarity of major themes	31	Were major themes clearly presented in the findings?	57
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	64-84

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