“Wherever I go I’ll always have it”: Experiences of adolescents with HIV treatment and care in Zambia

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Declaration

I, Kasonde Marie Madeleine Mwaba confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signed:

Abstract

Adolescents living with HIV (ALHIV) are making up an increasing number of new infections globally, however HIV treatment outcomes among this population remain poor, especially in resource limited settings. Sub-Saharan Africa (SSA) has the largest number of ALHIV where AIDS is a leading cause of adolescent death. Despite the poor health outcomes among ALHIV in resource-limited settings in SSA not much is known about the psychosocial factors affecting the experiences of ALHIV in Zambia, including with engagement with the HIV care continuum. There are also limited studies examining the perceptions and experiences of ALHIV across the life course, including with self-disclosure, advanced treatment regimens and transitioning from pediatric to adult HIV care. There are also limited qualitative studies exploring these experiences from the perspective of health service providers, who play a key role in care provision and support.

Despite increased access to antiretroviral therapy (ART) in low resource settings, ALHIV continue to struggle, indicating the need to examine factors within the social environment that impede engagement with the HIV care continuum and improved treatment outcomes in this population. To gain an understanding of these challenges the primary objective of this thesis is to identify psychosocial factors affecting the lived experiences of ALHIV and their engagement with the HIV care continuum in Lusaka, Zambia using the HIV care continuum as an organizing framework. This thesis includes a systematic review exploring the self-disclosure experiences of ALHIV in SSA and a depth analysis of the lived experiences of ALHIV from the perspectives of adolescents and health service providers in Zambia. Participants were recruited from clinics and NGOs in Lusaka between December 2018 and April 2019. The semi-structured interviews were analyzed using thematic network analysis.

Findings from the systematic review identified 4372 articles from the search, with 14 articles eligible for inclusion. Data extraction and analysis found low rates of self-disclosure among ALHIV, and identified motivations, facilitators and barriers to disclosure. Barriers to disclosure included fears of rejection, abandonment and onward disclosure of HIV status. Findings from the adolescent in-depth analyses identified various factors shaping the lived experiences of ALHIV including individual, relational and health system related factors. It also identified important challenges to treatment engagement and changing experiences across the life course, including learning of HIV status, coping, managing adherence in the context of everyday life, managing anticipated stigma, disclosure of HIV status. These findings illustrate how psychosocial factors within the environment shape adolescent experiences navigating living with HIV across the life course, which are further compounded by the stressors related to adolescence.

The health service provider findings identified perceptions of health service providers on the challenges faced by ALHIV and underlined unique challenges encountered by this group working with adolescent populations. The findings showed that health service providers are knowledgeable of the challenges faced by ALHIV, especially regarding engagement with treatment services however, they are limited in their ability to respond to the needs of adolescents due to the restrictive social contexts in which they work. These findings highlight the need for interventions targeting the social environment, especially socioeconomic and public policy aspects that significantly affect adolescent treatment experiences and access to health services.

In sum, this body of work showed that diverse factors affect the experiences of adolescents across the HIV care continuum and that the experiences and needs of ALHIV change across the life course. These accounts highlight the need for the creation of enabling social environments that enhance adolescent engagement in treatment and care and improve their quality of life. My data suggests that such interventions must be multi-faceted and address factors at multiple levels of the social environment with consideration of key stages of development. The root causes producing and maintaining risks in the social environment must be addressed for any gains in the control of the adolescent HIV epidemic to be sustained, as unmediated social contexts undermine improvements in treatment outcomes and the goal to end the HIV epidemic by 2030. It is hoped that the findings from this thesis will enable stakeholders to better understand and address the needs of ALHIV, especially across adolescence and into adulthood and inform future research into the experiences of adolescents.

Impact statement

AIDS is the second leading cause of death among adolescents in Sub-Saharan Africa and HIV infections are increasing among adolescents, who make up an increasing share of new adult HIV infections. Despite the increasing availability of ART, adolescents have poor HIV treatment outcomes, especially compared to those of adults. This thesis examined the experiences of adolescents across the HIV care continuum and explored and identified psychosocial factors influencing the experiences of ALHIV using a socio-ecological lens. The findings identified a variety of psychosocial factors within the social environment that produce and maintain risks to the health and wellbeing of ALHIV. The findings of this thesis contribute to the literature on the lived experiences of ALHIV, including their experiences with self-disclosure and challenges faced across the life course and the limited literature on the perceptions and experiences of HSPs working with ALHIV in resource limited settings.

Practice

Findings will enhance the understanding of stakeholders at the local, national and global level of the experiences and the various challenges faced by ALHIV in resource limited settings. The findings can inform changes to health practices and behaviors within health facilities, including the availability and accessibility of services to adolescents and inform the development of interventions to address the needs of ALHIV across the life course. The adapted socio-ecological model and proposed conceptual model of medication adherence among ALHIV outlined in this thesis are accessible models that stakeholders can refer to. These models have the potential to inform changes in practice and service delivery to meet the various needs of adolescents living in resource limited settings.

Policy

Findings can inform the development of adolescent health policies, as they highlight challenges within the social environment that undermine the control of the HIV epidemic and access to health services faced by this population. The results support revision of SRH policies that restrict access to health services, including HIV testing and family planning to adolescents below the age of 16. These factors contribute to low testing rates among ALHIV and engagement in risky sexual behaviors which have implications for onward transmission of HIV.

Findings highlight the need for multi-level interventions addressing factors across socio-ecological levels. Potential interventions addressing these factors are discussed in the final chapter and include interventions to support the disclosure process, address socio-economic barriers, HIV-related stigma, and health facility and policy level changes. They stress the need for the creation of an enabling social environment to enhance the health and wellbeing of ALHIV and to provide HSPs with the necessary tools to respond to the unique needs of this population.

Future research

Findings from this thesis highlight areas for future research into the experiences of ALHIV. For example it highlights the need for studies into the experiences of younger adolescents. It also highlights factors that can be further investigated in future studies of the lived experiences of ALHIV and proposes a conceptual framework that can be tested or applied in different settings.

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Publications and presentations

Publications

Mwaba, K., Mannell, J., Burgess, R. and Sherr, L., 2020. Uptake of HIV testing among 15–19-year-old adolescents in Zambia. *AIDS care*, *32*(sup2), pp.183-192.

Mwaba, K., Senyurek, G., Ulman, Y., Minckas, N., Hughes, P., Paphitis, S., Andrabi, S., Salem, L., Ahmad, L., Ahmad, A. and Mannell, J.,"My story is like a magic wand": A qualitative study of personal storytelling and activism to stop violence against women in Turkey. Global Health Action, DOI: 10.1080/16549716.2021.1927331

Under preparation

"It's now part of my life": Experiences of Adolescents Living with HIV in Lusaka, Zambia

"Our hands are tied": Health service provider perspectives and experiences engaging ALHIV in care in Lusaka, Zambia

Conference presentations/talks

Mwaba K. *Predictors of HIV testing among older adolescents in Zambia.* Findings from this analysis were presented as a poster at the AIDSImpact Conference, London UK, July 2019. http://www.aidsimpact.com/.

"I just thought my world has ended, my game is over" Experiences of ALHIV in Lusaka. Presentation given at the Institute for Global Health post-graduate research seminar on 20th November 2020.

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List of abbreviations

AFHS: Adolescent Friendly Health Services

AGYW: Adolescent Girls and Young Women

AIDS: Acquired Immunodeficiency Syndrome

ANC: Antenatal Care

ART: Antiretroviral Therapy

ATC: Advanced Treatment Center

CAG: Community Adherence Group

CHAZ: Churches Health Association of Zambia

DHO: District Health Office

DSD: Differentiated Service Delivery

eMTCT: Elimination of Mother To Child Transmission

HBM: Health Belief Model

HIV: Human Immunodeficiency Virus

HIV+: HIV positive

HSP: Health Service Provider

HTC: HIV Testing and Counselling

IMB Model: Information, Motivation and Behavioral skills Model

LA: Long Acting

MMAT: Mixed Methods Appraisal Tool

MOH: Ministry of Health

MTCT: Mother-to-child transmission

NAC: National AIDS Council

NASF: National HIV and AIDS Strategic Framework

NGO: Non-governmental organization

NHSP: National Health Strategic Plan

PMTCT: Prevention of mother-to-child transmission

PRISMA: Preferred Reporting Items for Systematic Review and Meta-Analysis

SBCC: Social Behavior Change Communications

SEM: Socio-ecological model

SMSR: Systematic Mixed Studies Review

SSA: Sub-Saharan Africa

UAG: Urban Adherence Groups

UNAIDS: Joint United Nations Programme for HIV/AIDS

WHO: World Health Organization

YFC: Youth Friendly Corner

YFHS: Youth Friendly Health Services

ZDHS: Zambia Demographic Health Survey

Overview

This is a thesis describing the lived experiences of adolescents living with HIV (ALHIV) in Zambia. The primary objective was to explore the psychosocial factors contributing to their lived experiences, especially their impact on HIV treatment engagement and persisting poor treatment outcomes. With a focus on context, I investigate the impact of the socio-ecological environment on the health and wellbeing of ALHIV in a resource limited setting as the challenges presented by this context in which ALHIV are embedded, e.g. poverty, poor infrastructure, limited social services, etc. significantly shape their experiences and health outcomes.

As a unique phase of development, the changes and challenges experienced during adolescence have implications on the treatment experiences and everyday lives of ALHIV. Adolescents experience various changes as they mature across the adolescent life stage and such experiences may have various consequences on treatment and the design of effective interventions targeting their unique needs. Therefore the in-depth analyses exploring the lived experiences of ALHIV examines their experiences with the HIV care continuum, specifically identifying challenges to adherence and retention in care and applies a life course approach to examine how factors across the life course influence their experiences.

This thesis uses the HIV continuum of care as an organizing framework to explore the diverse socio-ecological factors influencing the lived experiences of ALHIV and draws on findings from a systematic review and in-depth qualitative research on ALHIV and health service providers. The thesis is comprised of eight chapters and each chapter begins with a brief introduction and concludes with a discussion providing an overview of the findings and contextualizing them within the literature. Below is a summary of the chapters comprising this thesis:

Chapter One: The adolescent HIV epidemic: current status, gap and implications for the control of the HIV epidemic

This chapter provides an overview of the adolescent HIV/AIDS epidemic at the global, regional and national levels, summarizes the current status of the epidemic and the challenges faced by ALHIV along the HIV care continuum in Sub-Saharan Africa (SSA). I also provide contextual data on the Zambian health system, the provision of HIV-related treatment and care services and the policy environment relating to adolescents and young people in Zambia. In order to better contextualize the unique challenges faced by ALHIV, I describe the developmental phase of adolescence, including the various developmental changes and challenges, their implications for controlling the adolescent HIV epidemic, discuss the life course approach and the literature on the lived experiences of ALHIV in SSA. I conclude this chapter by outlining the gaps in the literature, the research questions guiding the study and how they will be achieved.

Chapter Two: Theoretical frameworks for understanding health behavior

This chapter describes the theoretical framework framing the research in this thesis. In this chapter I describe three commonly used frameworks applied to understand HIV-related health behavior. I describe each framework in turn, and begin by describing its origins; constructs; application to the study of health behaviors in adolescents and the study of HIV/AIDS in particular; strengths and limitations; and their applicability in examining the experiences of ALHIV. This chapter concludes with a description of the theoretical framework guiding this thesis, the Social Ecological Model (SEM), which was chosen for its utility in contextualizing the experiences of ALHIV within the social environment, and also describes how the model is applied in this thesis. The socio-ecological lens aligns with the continuum of care organizing this thesis as it supports the identification of factors affecting the experiences of adolescents at various socio-ecological levels across the life course.

Chapter Three: Self-disclosure experiences of ALHIV in Sub-Saharan Africa: a systematic mixed studies review

This chapter presents the findings from a systematic review on the self-disclosure experiences of ALHIV in SSA. It is important that the self-disclosure behaviors of ALHIV are understood because of the implications they have for treatment and HIV prevention. The research questions guiding the review are: What are the perceptions and experiences of ALHIV towards self-disclosure of HIV status? What is the impact of self-disclosure on the wellbeing of adolescents? What are the barriers and facilitators to self-disclosure? What interventions exist to enable self-disclosure among ALHIV? The results reveal numerous barriers and negative consequences associated with self-disclosure.

Chapter Four: Understanding relationships between context and experience: methodological considerations

This chapter describes the methodology and research design concerning the in-depth analyses into the lived experiences of ALHIV. I outline the epistemological assumption influencing the research and its alignment with the theoretical framework guiding this thesis (SEM). I also describe the data collection and analysis process. The data were collected using semi-structured interviews with ALHIV aged 15-20 and health service providers and were analyzed using thematic network analysis. I also describe the application of the life course approach and conclude with a reflection on my experiences during the research process.

Chapter Five: “Sometimes I would just get the medicine throw it away and lie that I’ve taken the medicine”: Experiences of ALHIV with the HIV care continuum

This chapter explores the perceptions and experiences of ALHIV with the HIV care continuum, highlighting the barriers they face with engagement with treatment and care services. The research questions framing the analysis are: What are the perceptions and experiences of ALHIV? What are their experiences with treatment and care? What challenges do they face and how do they cope? Findings discuss experiences with discovery of HIV status, coping, challenges with adherence and retention in care and stigma.

Chapter Six: “Last year they used to remind me that it’s time for your medicine but ah, this year now I’m a grown-up person”: A life course approach to understanding the experiences of ALHIV

This chapter applies a life course approach to explore the experiences and challenges ALHIV face across the life course and the factors influencing these experiences. The findings highlight various events, transitions and challenges ALHIV face as they navigate living with HIV. The findings also build upon and contextualize the findings from the systematic review in the local context, as it describes participant experiences and perceptions relating to disclosure of their HIV status, addressing important gaps in the literature.

Chapter Seven: “Our hands are tied”: Health Service Provider perspectives on the experiences of ALHIV

This chapter explores the perspectives of health service providers (HSPs) working in both clinical (health facilities) and community settings (NGOs) on the experiences of ALHIV with the HIV care continuum and their experiences providing services to them. The research questions framing the analysis are: What are the perceptions of HSPs on the experiences and challenges faced by

ALHIV? What issues or challenges do they face in working with adolescents? What are their perceptions of what can/should be done to better support ALHIV? The findings from this study highlight factors shaping the experiences of ALHIV across the HIV care continuum and undermining treatment engagement at various socio-ecological levels. The findings from this chapter are triangulated with the findings from the previous adolescent chapters.

Chapter Eight: Reflections, contributions and recommendations on research into the lived experiences of ALHIV in resource limited contexts

In this concluding chapter, I bring together the findings from chapters three, five, six and seven and discuss them in light of the research aims stated at the outset of this thesis. I summarize the key findings of the study and contributions to the literature. I also present an adapted SEM illustrating the multi-level factors shaping the experiences of ALHIV and propose a conceptual framework describing health decision making and behavior concerning medication adherence among ALHIV in resource limited settings based on the findings of this thesis. This chapter concludes with a discussion of the limitations of the study and recommendations for practice and interventions, policy and future research.

Chapter 1 The adolescent HIV epidemic: current status, gaps and implications for the control of the HIV epidemic

This chapter provides an overview of the adolescent HIV epidemic, providing information on the current status of the epidemic at the global, regional, and national levels. It provides key contextual information on Zambia, the national HIV/AIDS response and policies and strategies concerning the health of young people in Zambia. It describes some of the key developmental challenges for adolescents and the implications of adolescence for controlling the adolescent HIV epidemic. It also introduces the life course approach, describing its application in the literature and its usefulness for examining lived experiences. Adolescent outcomes along the HIV care continuum at the regional level (including HIV testing, and linkage and retention in treatment) and literature on the lived experiences of ALHIV are also discussed. Finally it summarizes gaps in the literature concerning the experiences of ALHIV and outlines the aims of this thesis and how they will be achieved.

1.1 Background

The Human Immunodeficiency Virus (HIV) is a virus that attacks an individual's immune system and compromises its ability to fight off infections and disease. It can be transmitted from an infected individual through sexual contact, sharing sharp objects and from mother-to-child during pregnancy, childbirth or breastfeeding. Without proper treatment, HIV can progress to AIDS - Acquired Immune Deficiency Syndrome (AIDS). There is no cure for HIV but it can be controlled through Antiretroviral Therapy (ART) which slows down the replication of the virus and greatly reduces the viral load in the body of a person living with

HIV which results in improved immune system functioning, reduction in the risk of HIV/AIDS related complications, opportunistic infections and onward transmission of HIV (Kalichman et al., 2010).

In 2018, there were 37.9 million people living with HIV (PLWH) and 1.7 million new infections globally (World Health Organization, 2021). 25.7 million PLWH and 1.1 million new infections were in Africa in 2018 (World Health Organization, 2021). Adolescents (defined as individuals aged between 10 and 19) (World Health Organization, 2001) are severely affected by the HIV epidemic. In 2019 there were 1.7 million Adolescents living with HIV (ALHIV) globally and 170,000 new infections in this population (United Nations Children's Fund, 2020). Adolescents also account for a growing share of new global HIV infections with UNICEF projections estimating that if current trends continue without intervention, new HIV infections among adolescents will amount to 183,000 per year in 2030 (United Nations Children's Fund, 2020). AIDS-related deaths among ALHIV is also of concern as adolescents are the only age category for which AIDS-related deaths have increased since 2000. In 2017 alone, over 20,000 deaths were recorded (The Lancet Child & Adolescent Health, 2018, Idele et al., 2014). 88% (1.5 million) of ALHIV live in Sub-Saharan Africa (SSA), where AIDS is a leading cause of death among adolescents (The United Nations Children's Fund, 2019, United Nations Children's Fund, 2016). ALHIV were either vertically or horizontally infected, with vertically infected adolescents having acquired HIV through mother-to-child-transmission (MTCT) either perinatally or postnatally while horizontally infected adolescents contract the virus through their own activity, e.g. unprotected sex with an HIV-infected individual, injecting drug use, etc.

Zambia is among the top ten countries with the highest numbers of PLWH in the world (Ministry of Health and National AIDS Council, n.d.). The most recent Zambia Demographic Health Survey (ZDHS) data revealed that in 2018 HIV prevalence among adolescents aged 15-19 in Zambia was 2.6% (Zambia Statistics Agency et al., 2019). However, what we know about the experiences of this population is fairly limited despite the burden of HIV in the country and its youthful population (Mburu et al., 2014b).

1.2 Zambia country background

Zambia is a land locked country in southern Africa with an area of about 752, 618 km^2 (Central Intelligence Agency, 2022) (see Figure 1-1). It borders Zimbabwe, Malawi, Mozambique, Tanzania, Democratic Republic of Congo, Namibia, Angola and Botswana. The terrain is mostly high plateau with some mountainous and hilly areas (Central Intelligence Agency, 2022). It is a former British colony and became a republic following independence on October 24th, 1964. It is governed using a presidential republic style of government in which the President is both the Chief Executive and Head of government (Central Intelligence Agency, 2022).The country is divided into ten administrative provinces: Central, Eastern, Copperbelt, Luapula, Lusaka, Northern, Muchinga, North-Western, Southern and Western and 105 districts (Ministry of Health, 2017b).

Figure 1-1: Map of Zambia[1]

Zambia has a population of 19,077,816 (2021) and 45.8% reside in urban areas (Central Intelligence Agency, 2022). The population is largely young with 48% under the age of 15 (Zambia Statistics Agency et al., 2019). The life expectancy at birth is 65.9 years (Central Intelligence Agency, 2022). The majority of the population either have some primary education or no formal education (Zambia Statistics Agency et al., 2019). The literacy rate was 86.7% in 2018 (90.6% among men and 83.1% among women) and was higher in urban areas compared to rural (Central Intelligence Agency, 2022). The economy is based on mining (particularly copper), agriculture, construction, communication and transport

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[1] Source: OnTheWorldMap.com

sectors (Ministry of Health, 2017b, Central Intelligence Agency, 2022). The World Bank classifies Zambia as a lower-middle income country (The World Bank, n.d.) and in 2020 the GDP per capita was estimated at US$3,300 (Central Intelligence Agency, 2022).

Zambia has high levels of poverty and inequality, with discrepancies observed by province, type of residence and education status (Zambia Statistics Agency et al., 2019). In 2015 more than 58% of the population lived below the poverty line (US$1.90) and three fourths of the poor live in rural areas (The World Bank, 2021, Ministry of Health, 2017b). 72% of households have access to improved water sources, 54% have access to improved sanitation facilities and 34% have access to electricity (Zambia Statistics Agency et al., 2019). Those living in urban areas have increased access to education, improved water and sanitation facilities and electricity (Zambia Statistics Agency et al., 2019, Central Intelligence Agency, 2022).The unemployment rate was 15% in 2008 and youth unemployment (15-24) reached 30.1% in 2019 (Central Intelligence Agency, 2022). Unemployment is more severe in urban areas, among youth, women and people with disabilities (Ministry of Health, 2017b). Other key national and socioeconomic and health indicators are displayed in Table 1-1 below.

Table 1-1: Key socioeconomic and health indicators

Indicator	**Rate/Years**
Birth rate (per 1000 people)	34.9 (2022 est.)[2]
Total fertility rate (children per woman)	4.7 (2018 est.)[3]
Life expectancy at birth (male)	64.2 (2021 est.)[2]
Life expectancy at birth (female)	67.8 (2021 est.)[2]
Maternal mortality rate (per 100,000 live births)	213 (2017 est.)[2]

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[2] Central Intelligence Agency: “Zambia”

[3] Zambia Demographic Health Survey 2018

Infant mortality rate (deaths per 1,000 live births)	37.9 (2021 est.) [2]
Under 5 mortality (deaths per 1,000 live births)	61 (2018 est.) [2]
Health expenditure (% of GDP)	5.3% (2019 est.)[2]
Physicians (per 1000 people)	1.19 (2018 est.) [2]
Education expenditure (% of GDP)	4.5% (2019 est.) [2]

Lusaka

Lusaka, where the qualitative research in this thesis takes place, is the capital and largest city in Zambia with a population of 3.04 million (Central Intelligence Agency, 2022). The city is located in Lusaka province which is subdivided into four districts: Lusaka, Chongwe, Kafue and Luangwa. In 2015 Lusaka province had a population of 2,777,439 with 14.3% living in rural areas and 85.7% urban areas (Central Statistical Office, 2016). The province is the most densely populated with 126.8 people per km^2 (Central Statistical Office, 2016). The most recent census (2010) found that 40.4% of the population in the district were under the age of 15 (Central Statistical Office, 2012a). Lusaka district is the largest district in the province and in 2010 had a population of 1,747,152, accounting for about 80% of the provincial population (Central Statistical Office, 2012a). Compared to the other provinces, Lusaka province has the highest percentage of the population in the highest wealth quintile (Zambia Statistics Agency et al., 2019) and the lowest incidence of poverty, accounting for 7% of the overall poverty in the country in 2015 (Central Statistical Office, 2016). The unemployment rate among individuals aged 12 and older was 26% (20.6% among men and 33.2% among women) in 2015 (Central Statistical Office, 2016). Regarding water and sanitation, 98% have access to an improved drinking water source and 80% have access to improved sanitation facilities (Zambia Statistics Agency et al., 2019). In addition, 70.6% of households in 2015 were connected to electricity (Central Statistical Office, 2016).

1.2.1 Disease burden

There has been significant progress in improving the health status of the population (e.g. declining MMR. IMR, HIV, etc.) in Zambia however, there is still a high burden of disease, including high rates of infectious disease (malaria, HIV/AIDS, sexually transmitted infections, TB) and rising rates of non-communicable disease (e.g. cancers, cardiovascular diseases, diabetes, chronic respiratory diseases, sickle cell anemia, mental health, etc.) (Ministry of Health, 2017b, World Health Organization, 2018, Ministry of Health, 2021a). Undernutrition is endemic in large parts of the country and poor sanitation infrastructure, inadequate water sources and poor hygiene practices contribute to yearly cholera outbreaks in densely populated peri-urban areas (World Health Organization, 2018). The top ten causes of mortality in 2020 are listed in the Table 1-1: Key socioeconomic and health indicatorsTable 1-2 below.

Table 1-2: Top 10 causes of mortality (2020)[4]

Disease	**%**
Malaria	14.6
Anemia	9.1
Cardiovascular diseases	8.5
Respiratory infection: pneumonia	7.2
Tuberculosis	6.3
Hypertension	5.8
Diarrhea (non-bloody)	3.9
Diabetes	3.6
Severe malnutrition	3.1
Digestive (non-infectious)	3.1

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[4] Source: Ministry of Health: Annual Health Statistical Report 2021

1.2.2 HIV/AIDS in Zambia

AIDS was first diagnosed in Zambia in 1984 and the Zambian government has been working collaboratively with both national and international partners in its epidemic response (Central Statistical Office et al., 2014). Zambia has a generalized epidemic with heterosexual transmission the main mode of infection (Ministry of Health Zambia and National AIDS Council, 2015). According to the National AIDS Council, the epidemic is primarily fueled by low and inconsistent condom use, multiple and concurrent partnerships, low coverage of male circumcision and MTCT (Ministry of Health and National AIDS Council, n.d.). In 2019 there were 1.4 million PLWH and the HIV prevalence rate among adults aged 15-49 was 11.5% (Joint United Nations Programme on HIV/AIDS, 2020). Women have a higher HIV prevalence than men and in 2018 the prevalence rate was 14.2% among women and was 7.5% among men (Zambia Statistics Agency et al., 2019). HIV prevalence is also higher in urban areas (15.9%) compared to rural (7.1%) (Zambia Statistics Agency et al., 2019). Lusaka province had the highest HIV positivity rate at 9.1% in 2020 (Ministry of Health, 2021a). There were also 51,000 people newly infected with HIV and 17,000 AIDS-related deaths in 2019 (Joint United Nations Programme on HIV/AIDS, 2020). Evaluations of the national progress on the UNAIDS 90-90-90 three part treatment target that outlined the goal that by 2020 90% of PLWH will be aware of their status, 90% will be receiving treatment and 90% will be virally suppressed, in 2019 found that 90% of PLWH in Zambia were aware of their HIV status, 85% were receiving ART and 77% were virally suppressed (Joint United Nations Programme on HIV/AIDS, 2020). However, on December 1st 2020 Zambia was officially recognized as having achieved the 90-90-90 treatment target (Ministry of Health, 2020).

1.3 Adolescents in Zambia

In 2015 adolescents accounted for 25% of the Zambian population (Ministry of Health, 2017a). Adolescents in Zambia face various socioeconomic challenges including poverty, access to education and unemployment (Ministry of Health, 2012). Important health challenges faced by adolescents in Zambia include communicable and non-communicable diseases, particularly HIV/AIDS, STIs, malaria, etc.; early and unprotected sex; early marriages and pregnancies; substance and alcohol abuse; accidents and violence and mental health problems (Ministry of Health, 2012).

School leavers are generally aged 18 (Central Statistical Office, 2016) however, most young people complete their education with only primary or lower secondary education (Population Council and United Nations Population Fund, 2018). The numbers of young people in education significantly drops between primary and secondary school. The primary school net attendance ratio (7-13 years) was 79% (81% among girls and 77% among boys) and the secondary school net attendance ratio (14-18 years) was 40% (42% among boys and 38% among girls) (Zambia Statistics Agency et al., 2019). Only 28% of those who enter the school system are able to complete secondary education (United Nations Educational Scientific and Cultural Organization, 2016). Reasons attributed to poor educational completion rates among young people include poor numeracy and literacy skills, the cost of secondary and tertiary education and limited spaces for higher level education (Population Council and United Nations Population Fund, 2018). Unemployment is also a significant challenge for out of school adolescents and/or those who have completed secondary school (Population Council and United Nations Population Fund, 2018, Central Statistical Office, 2016).

In 2018 15% of adolescent girls aged 15-19 were in a union compared to 1% of adolescent boys and 2% of girls were married by the age of 15 compared to less than 1% of boys (Zambia Statistics Agency et al., 2019). Despite the age of consent for sexual activities being 16 years in Zambia (SRHR Africa Trust, 2018), about 13% of girls and 16% of boys aged 15-19 reported having had sex before the age of 15 in 2018 (Zambia Statistics Agency et al., 2019). The percentage of those reporting sex before the age of 15 is higher in rural areas and declines with increasing levels of education (Zambia Statistics Agency et al., 2019). In 2018 0.9% of adolescent girls and 5.9% of boys aged 15-19 reported having two or more sexual partners and 2% of girls reported having had sex with a partner who was at least 10 years older than them (Zambia Statistics Agency et al., 2019). Zambia has the fifth highest adolescent birth rate in SSA (Ministry of Health, 2017b). In 2018 29% of females aged 15-19 had begun childbearing (19% in urban areas and 37% in rural) (Zambia Statistics Agency et al., 2019) and in 2020 teenagers accounted for 24.9% of total first antenatal visits (Ministry of Health, 2021a). Among adolescents aged 15-19, 40.5% of girls and 38.6% boys had comprehensive knowledge of HIV (Zambia Statistics Agency et al., 2019). Despite the SRH challenges faced by this population, current SRH policy restricts access to SRH services including HIV testing and family planning without parental consent to individuals from the age of 16 (Ministry of Health, 2017a, Ministry of Health and National AIDS Council, 2017).

HIV/AIDS among adolescents in Zambia

Around the time this study began in 2017, adolescent girls accounted for 4.8% and adolescent boys accounted for 4.1% of the Zambian population living with HIV (Ministry of Health, 2017b). The most recent demographic survey data from 2018 indicates that the HIV prevalence rate was 1.9% among adolescents aged 15-19 and that it was higher among girls (2.6%) than boys (1.2%) (Zambia Statistics Agency et al., 2019). Adolescent girls are disproportionately affected by HIV due to biological, cultural and behavioral factors (Ministry of Health and National AIDS Council, 2017). HIV prevalence among those aged 15-17 was 1.6% and 2.4% among those aged 18-19 (Zambia Statistics Agency et al., 2019). Among youth aged 15-24, HIV prevalence (3.8%) was higher among those living in urban compared to rural areas (Zambia Statistics Agency et al., 2019) and almost three fifths are living with undiagnosed HIV infection (Ministry of Health, 2019). More than 25% of young people aged 15-24 living with HIV are virally suppressed (Ministry of Health, 2019). Data on HIV/AIDS among adolescents is limited, especially concerning younger adolescents (e.g. aged 10-14).

1.4 Addressing population health: Zambia Health System overview

Zambia has a primary health care system with decentralized responsibility for the coordination and delivery of health services at the provincial and district levels (Ministry of Health, 2017b). There are four key players involved in the delivery of health services: public health sector (government owned and operated facilities), faith-based (not for profit) providers, mine-owned health facilities and private (for profit) providers (Ministry of Health, 2017b, Ministry of Health, n.d.). However, over 90% of the population seeks care from facilities that are owned and run by the government (Central Statistical Office, 2012b).

At the national level, the Ministry of Health (MOH) is responsible for overall coordination and management, strategic planning, policy formulation and resource mobilization in the health sector (Ministry of Health, 2017b). At the provincial level, the Provincial Health Office (PHO) is responsible for supporting provincial and district health services and providing referral services at second-level hospitals (provincial or general hospitals) (Ministry of Health, 2017b). At the district level, the District Health Office (DHO) is responsible for implementing preventive, curative, rehabilitative and health promotion services (Ministry of Health, 2017b). District hospitals are located in every district and provide first-level referral services. Public health care services are provided in a three tier referral system at primary (health posts, health centers and district hospitals), secondary (provincial or general hospitals) and tertiary (specialist hospitals) levels (See Table 1-3) with patients referred to higher levels of care as necessary (Ministry of Health, n.d.).

Table 1-3: Type of public health facilities

Level	Facility	n	Services
Primary	Health post	953[5]	• Health promotion and preventive activities[6]
Primary	Health center	1,839[5]	• Health promotion and disease prevention activities[6] • Responsible for the delivery of key health programs that include communicable and non-communicable diseases, epidemic preparedness, maternal and child health, etc. [6]
Primary	Frst level or District hospitals	99[5]	• Medical, surgical, diagnostic, obstetrics,clinical and preventive services[6]
Secondary	Second level or Provincial hospitals	34[5]	• General surgery, internal medicine, pediatrics, obstetric and gynecology, dental care, intensive care and psychiatry services[6]
Tertiary	Third level or Specialist hopsitals	8[5]	• Sub-specializations in surgery, pediatrics, obstetrics, gynaecology, internal medicine, intensive care, psychiatry, training and research[6]

The Churches Health Association of Zambia (CHAZ) runs health institutions including hospitals and health centers which account for about 30% of national health coverage and more than 50% of rural health care services across the country (Ministry of Health, n.d.). CHAZ owns 8 of the 34 second level hospitals in the country (Ministry of Health, 2017b). The association was formed by Catholic and Protestant missionary health workers in 1970 with the aim of improving the organizational effectiveness of church health institutions and church based community organizations that were involved in health service delivery in the country (Ministry of Health, n.d.). Mine owned health facilities provide health care

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[5] Zambia National Health Strategic Plan 2017-2021
[6] National Community Health Strategy 2019-2021

services primarily for their staff however, non-staff are able to access services for a fee (Ministry of Health, n.d.). The private health sector which includes private clinics and hospitals, provides care to about 3% of the population (Ministry of Health, n.d.).

The public health system faces many challenges, including inadequate funding, shortage of health workers, shortages of drugs and medical supplies, weak health information management systems, inadequate equipment and infrastructure and service disparities between urban and rural areas (World Health Organization, 2018, Ministry of Health, 2017b, Association of Chartered Certified Accountants, 2013, Zambia Development Agency, 2013). Like in other limited resource settings, the structural challenges with health service delivery affect Zambia's capacity to respond to the HIV/AIDs epidemic. These include low government health spending (Mooketsane and Phirinyane, 2015, Bollyky et al., 2017, Musango et al., 2012, Malakoane et al., 2020, Audibert and Mathonnat, 2013, Oleribe et al., 2019); inadequate material (Charan and Paramita, 2016, Hanson et al., 2003, Ritchie et al., 2016, Agyeman-Duah et al., 2014, Mooketsane and Phirinyane, 2015) and human resources (Ritchie et al., 2016, Mooketsane and Phirinyane, 2015, Oleribe et al., 2019, Agyeman-Duah et al., 2014, Hanson et al., 2003, Jenkins et al., 2011), including the shortage and uneven distribution of health workers (Oleribe et al., 2019, Agyepong et al., 2017, Ritchie et al., 2016, Mbemba et al., 2016, Fairall et al., 2015, Chen et al., 2004, Roncarolo et al., 2017, Yumkella, 2006, Bangdiwala et al., 2010, Zihindula et al., 2019, Sherr et al., 2012); weak health system management (Govender, 2005, Oleribe et al., 2019, Hanson et al., 2003, Mooketsane and Phirinyane, 2015, Malakoane et al., 2020); and poor governance and corruption (Hanson et al., 2003) which result in poor health outcomes by undermining access and delivery of health services (Vian, 2008, Naher et al., 2020, Oleribe et al., 2019, Hsiao et al., 2019, Onwujekwe et al., 2018, Bruckner, 2019). In light of these challenges, NGOs play a critical role in supporting health systems in low-resource settings (Hecht and Tanzi, 1994, Mercer et al., 2004, Kelly et al., 2006, Kebede, 2004), filling gaps in health service delivery (Hushie et al., 2016, Yagub and Mtshali, 2015, Ejaz et al., 2011), providing health system financing (Kebede, 2004, Yagub and Mtshali, 2015, Mtei et al., 2007, Shaw et al., 2015) and addressing health worker shortages (Zihindula et al., 2019, Yagub and Mtshali, 2015). Zambia’s health care system faces similar challenges described above and as a result the government heavily relies on support from donors and NGOs in its HIV/AIDS response (Ministry of Health and National AIDS Council, n.d.).

1.4.1 Using public policy to address national health challenges

In response to the burden of disease and to address the challenges facing the health sector, national policies and strategies guide the implementation and coordination of efforts to address the health needs of the Zambian population and are guided by the MOH’s mission to provide accessible and quality health services (Ministry of Health, 2017b). At the time the research was being conducted in this thesis, the government of Zambia was implementing the National Health Strategic Plan (NHSP) 2017-2021 which outlined the direction, interventions, roles and responsibilities for the health sector between 2017 and 2021 (Ministry of Health, 2017b). The plan aims to improve the health and productivity of the population by focusing on strengthening health systems and services using a primary health care approach and aligns with the Zambian government’s Zambia Vision 2030 strategy, which aims to transform Zambia into “a prosperous middle income country” by 2030 (Ministry of Health, 2017b, p. 82). The NHSP identifies ending the HIV epidemic and improving HIV treatment as priorities and aligns with The National AIDS Strategic Framework (NASF) 2017-2021 which outlines the government’s multisectoral response to the HIV/AIDS epidemic including the overall strategy for planning, coordinating and implementing the multi-sectoral national response and the roles and responsibilities of various partners e.g. civil society, private sector, etc. (Ministry of Health and National AIDS Council, 2017). The strategy recognizes adolescent girls and young women as one of twelve key priority groups. Some of the strategic interventions described in the plan include scaling up social and behavior change communications (SBCC), comprehensive condom programming, voluntary medical male circumcision, STI screening and treatment, HIV testing services (HTS), elimination of mother to child transmission (eMTCT) and ART (Ministry of Health and National AIDS Council, 2017).

The health frameworks and strategies developed by the MOH are in line with other key international (e.g. The Sustainable Development Goals), regional (e.g. Abuja Declaration, The East and Southern Africa Commitment) and national (e.g.2006 School and Nutrition Policy, 2015 National Youth Policy, National Development Plans; Vision 2030; etc.) development policies and goals (Ministry of Health, 2017b, Ministry of Health, 2017a). These national policies are important for addressing the health and wellbeing of ALHIV because they target key contextual challenges faced by young people in Zambia that increase their risks of experiencing poor health and wellbeing (e.g. access to education, employment opportunities, accessible health services, etc.).

Using health policies/frameworks to address adolescent health challenges

Young people in Zambia face numerous challenges as a result of poverty, access to education and unemployment. The Zambian government's commitment to empowering and improving the health and wellbeing of youth who are defined as individuals aged between 15 and 35 years old (Ministry of Youth and Sport, 2015) is exemplified in the signing and ratification of international and regional charters on the rights of young people. These include the 1990 United Nations Charter on the Rights of the Child, the Organization of African Unity African Charter on the Rights and Welfare of the Child and the Reproductive Health Strategy for the African region (Ministry of Health, 2012).

Nationally, the 2015 National Youth Policy follows from the previous 1994 and 2006 youth policies and outlines the government's priorities to help youth realize their full potential and contribute to national development (Ministry of Youth and Sport, 2015). The policy identifies specific target populations which include youth affected by STIs and/or HIV/AIDS (in addition to: unemployed youth, migrant youth, youth headed households, out of school youth) and outlines key interventions across seven thematic areas including employment and entrepreneurship development, education and skills development, and health to empower Zambia’s youth (Ministry of Youth and Sport, 2015). However, the National Youth Policy does not highlight or address the needs of younger adolescents aged 10-14. Despite the government’s commitment to improving the lives of young people, their strategies and their associated policies, programs and activities are often poorly implemented, lack accountability and sufficient resources (e.g. financial and human) (Ministry of Health, 2017b, Population Council and United Nations Population Fund, 2018).

It is only within the last decade that national policies and strategies have been developed that specifically target the health needs of adolescents (See Table 1-4). For example, the first Adolescent Health Strategy and National Standards of Care for the delivery of Adolescent Friendly Health Services (AFHS) were only developed in 2011 (Ministry of Health, 2017a). Some of the strategies to improve support for young people outlined in the Adolescent Health Strategy 2017-2021 include scaling up SBCC to raise awareness and utilization of HIV/SRH services; improve quality and targeting of HIV prevention and treatment services; scale up gender sensitive and adolescent responsive health services; strengthen the coordination of adolescent programs at all levels and the monitoring and evaluation systems related to HIV/SRH programs that target adolescents (Ministry of Health, 2017a).

Table 1-4: Summary of recent adolescent targeted policies/strategies

Policy	**Summary of adolescent focused objectives**
National Standards and Guidelines for Adolescent Friendly Health Services (2011)	• Provides a guide for a comprehensive and coordinated response to adolescent health and development needs • Outlines a basic package of health services for health facilities to implement to increase quality health services available to adoelscents and increase adolescent access to health services
Adolescent Health Strategic Plan 2011-2015	• Provides a strategic framework for the coordination and delivery of comprehensive AFHS • Priority areas include SRH (family planning, sexual abuse, unsafe abortions and unprotected sex); health promotion and behavior change; communicable diseases (e.g.HIV/AIDS, STIs, TB and malaria); and non-communicable diseases (e.g. drugs, alcohol and substance abuse, unsafe cultural practices, violence, mental health, nutrition and healthy living)
2015 National Youth Policy	• Health focused objective aims to improve the health and wellbeing of adolescents. • Includes a provision to strengthen support for the SRH, rights and needs of adolescents.
National AIDS Strategic Framework 2017-2021	• Aims to intensify combination HIV prevention and improve access to quality HIV care and treatment services. • Identifies adolescents aged 15-19 as a key population and outlines specific strategies targetting young people (e.g scaling up gender sensitive and adolescent

	responsive health services; strengthening the coordination of adolescent programs at all levels and the monitoring and evaluation of adolescent HIV/SRH programs).
Adolescent Health Strategy 2017-2021	• Aims to improve the health status of adolescents through strengthening the delivery of health services that are responsive to adolescent needs (e.g scaling up ADH services), increasing access utilization of quality health care services in this population and strengthening the leadership and governance to deliver adolescent responsive health services. • Areas in need of increased attention were identified and include: SRH, HIV/AIDS and other STIs, gender based violence, non-communicable diseases, drug and substance abuse and issues facing adolescents with special needs. • In line with National Health Strategic Plan 2017-2021.

The recognition of adolescents as a key population has largely occurred in the absence of implementation and establishment of functional accountability and support structures – which is crucial for achieving impact, as has been seen elsewhere (Danhoundo et al., 2018, Debie et al., 2022, Ciccone et al., 2014). Specific gaps and challenges facing efforts to improve adolescent health include isolated/fragmented efforts; poor and inadequate implementation of adolescent health strategies; poor accountability and implementing structures at the local level; inadequate funding for adolescent health programs; service related challenges (e.g. inadequate HIV/SRH outreach services for adolescents, poor knowledge of adolescent health issues among health workers, shortage of health workers, inadequate medical and reproductive health commodities targeting adolescents, lack of adolescent specific health indicators in the national health management information system, etc.) and restrictive policies and legal frameworks (Ministry of Health, 2017b, Ministry of Health, 2012).

1.4.2 Adolescent HIV treatment and care

The National AIDS Council (NAC) was created in 2002 and is tasked with coordinating the national HIV/AIDS response (World Health Organization, 2005). It plays a key role in the development and implementation of the National HIV and AIDS Strategic Framework (NASF) that outlines the national multi-sectoral HIV/AIDS response (Ministry of Health and National AIDS Council, 2017). In 2005, access to ART services became free of charge in public sector facilities (World Health Organization, 2005) and in 2017, Zambia introduced the test and start policy, in which anyone testing positive for HIV is initiated on ART (Ministry of Health and National AIDS Council, n.d.). HIV treatment and care services are provided through ART clinics offered at a number of health facilities across the country and at the end of 2016 there were over 1,800 facilities offering HIV Testing and Counselling (HTC) services, over 870 ART sites and 800,000 PLWH on ART (Ministry of Health and National AIDS Council, 2017).

The care provided to adolescents is guided by the Zambia Consolidated Guidelines for treatment and prevention of HIV infections and the Adolescent HIV Guidelines (Ministry of Health and National AIDS Council, 2020). Generally upon diagnosis, adolescents are initiated on ART immediately or within 2 weeks of diagnosis and treated with first-line regimen and asked to return for evaluation after two weeks, then after four weeks post initiation and then after three months post-initiation and then every 3 months if stable (Ministry of Health, 2018).

Adolescents and adults are considered to be failing on treatment if they experience two consecutive viral load measurements of >1000 copies/mL within three months, with the provision of adherence support in between and after six months of combination ART (Ministry of Health, 2021b, Ministry of Health, 2020).

Access to third line regimens is very limited and its provision requires specialist knowledge which is often beyond the scope of most ART providers therefore, individuals are often referred to Advanced Treatment Centers (ATCs) which have specialized staff and offer care for the treatment of complicated/complex patients living with HIV (Ministry of Health, 2021b). Differentiated Service Delivery (DSD) models are starting to gain traction in Zambia and the MOH supports and promotes their application due to their potential to reduce the burden of frequent visits to health facilities on both the individuals and health care providers and promote the efficient use of limited resources (Ministry of Health, 2021b). In 2018 there were five main types of DSD models in use in the country including conventional care, community adherence groups (CAGs), mobile ART, urban adherence groups (UAGs) and home ART delivery (Nichols et al., 2021). The main types were offered to stable patients only except for mobile ART delivery (Nichols et al., 2021). These models are especially encouraged for stable clients which are defined as having been on ART for at least six months, having no adverse drug reactions, a proven record of good adherence and evidence of treatment success, no current illnesses or pregnancy and viral suppression within the last 12 months (Ministry of Health, 2021b).

Currently there are no health facilities offering comprehensive AFHS packages in Zambia (Ministry of Health, 2017a, Ministry of Health, 2012). Despite the lack of adolescent specific health policies at the time, Youth Friendly Corners (YFCs) were introduced in 1994 at some health facilities on a pilot basis by NGOs to facilitate access to health services for adolescents, youth and young adults aged 10-35 (Ministry of Health, 2012). YFCs provide Youth Friendly Health Services (YFHS) including peer counseling, screening and testing for STIs, HTC, family planning, health promotion and education, referrals for common health issues and facilitating access to health service providers (Ministry of Health, 2012). Within YFCs, youth are initially attended to by peer counselors and counselled before they are referred to the appropriate health care workers (Ministry of Health, 2012).Therefore, ALHIV are able to access health services through YFCs (where available) or standard health services that are offered to the general public. However, the services offered by YFCs are not targeted to meet the specific needs of adolescents as their services target a wider audience including youth and young adults (up to age 35). Adolescents are generally transferred to adult care between the ages of 19-24 (Elizabeth Glaser Pediatric AIDS Foundation, n.d.) as it varies by clinic as observed during fieldwork.

1.5 Adolescence: implications for the care and treatment of ALHIV

Exploring the experiences of ALHIV should be done in the context of an understanding of adolescent development, as it promotes a better understanding of the realities and challenges faced by ALHIV and highlights potential implications of adolescence on wellbeing and engagement in HIV treatment and care during this life stage. Adolescence is the transitional period between childhood and adulthood during which individuals experience many developmental changes including cognitive, physical, emotional, and behavioral (McNeely and Blanchard, 2010). The changes and challenges experienced during the stage of adolescence may further complicate the lives of adolescents who are navigating living with a stigmatized illness such as HIV (Mutumba et al., 2015a). Below I describe some of the key cognitive, physical, emotional, social and sexual changes adolescents experience.

Cognitive development

During adolescence individuals experience a strengthening of their advanced reasoning skills, develop the ability to think abstractly, and increase their capacity for meta-cognition (the ability to think about thinking) (McNeely and Blanchard, 2010). According to Sanders (2013), the capacity for meta-cognition allows adolescents to develop their abstract thinking skills and consider how they perceive and are perceived by others. In strengthening their reasoning skills adolescents are able to explore multiple possibilities and options and think hypothetically and logically (McNeely and Blanchard, 2010, Sanders, 2013).

Increasing cognitive maturity also allows adolescents to begin thinking about their future and setting goals (McNeely and Blanchard, 2010, Sanders, 2013). ALHIV face increased risks to normal cognitive development (Bekker and Hosek, 2015, Phillips et al., 2016). Phillips et al. (2016) found that perinatally infected children and adolescents experience higher prevalence of cognitive impairments in executive functioning, processing speed and working memory. This may increase their risks of experiencing emotional, social and educational challenges.

According to McNeely and Blanchard (2010), variation in the timing of physical and cognitive development can lead adolescents to experience issues with their body image which can be influenced by perceptions, emotions, experience, moods, physical sensations, societal standards and cultural messages. Body image issues may increase the risk of adolescents experiencing mental health issues, e.g. psychological distress and depression. This is concerning as mental health problems are common during adolescence, with half of adult mental health problems beginning before the age of 14 (Salmela-Aro, 2011, Knopf et al., 2008, Campbell et al., 2021).There are also sex and gender differences in the experience of mental health issues among young people. In a cross-national study, Campbell et al. (2021) found that girls experience poorer mental health compared to boys, especially concerning psychological distress and life satisfaction. Prevalence of depressive symptoms also increase with age during adolescence, increasing during early to mid-adolescence (e.g. 13-15 years old) and peaking during late adolescence (e.g. 17-18 years old) (Salmela-Aro, 2011), with girls more at risk of experiencing it (Dyer and Wade, 2012). This has implications for adolescent wellbeing as depressed adolescents have an increased risk of suicide, substance abuse and mental health disorders (e.g. anxiety), and behavior disorders (Salmela-Aro, 2011).

Physical development

Physical changes in adolescence begin with the onset of puberty in which adolescent girls and boys experience biological and physical changes (McNeely and Blanchard, 2010). Girls usually begin puberty before boys, and changes include changes in height, widening of hips, development of breasts, pubic and under arm hair, enlargement of ovaries, uterus, labia and clitoris and the onset of menstruation (McNeely and Blanchard, 2010). Physical changes in boys include changes in height and growth in their hands and feet, development of body and facial hair, pubic hair, enlargement of testicles and the lengthening of the penis (McNeely and Blanchard, 2010). However, the timing and speed of changes varies among and within individuals, and is influenced by both individual characteristics, e.g. sex and external factors, e.g. environment (World Health Organization, 2020).This variation in physical development may lead to the experience of body issues among adolescents as described above.

Challenges with physical development may be exacerbated in perinatally infected ALHIV, who may experience delayed onset of puberty as a result of their HIV infection (Bekker and Hosek, 2015). ALHIV in resource limited settings may also be at increased risk of physical delays as a result of poor nutrition and other context-related stressors.

Emotional and Social development

During the adolescent period, young people develop emotional and social competence. Emotional competence refers to the ability to understand and manage one’s emotions, while social competence refers to the capacity to get along well with others and form and maintain relationships (Weiner and Craighead, 2010). These capacities require adolescents to develop emotional intelligence, which refer to the necessary skills for managing emotions and relationships. These skills include self and social awareness and self-management (McNeely and Blanchard, 2010).

Adolescents also begin forming a sense of identity, which includes how they perceive themselves and how they fit in the world (McNeely and Blanchard, 2010). Two important aspects of identity development include self-concept and self-esteem. Self-concept refers to the way an individual perceives themselves and self-esteem refers to their perception of their self-worth (Sanders, 2013). The process of establishing ones identity includes increasing autonomy, mastery or sense of competence, forming social status, experiencing intimacy and development of sexual identity (McNeely and Blanchard, 2010). Adolescents also begin to distance themselves from their parents and shift towards their peers (Stangor and Walinga, 2010).

Peer relationships become increasingly important during adolescence, as individuals begin spending more time with their peers and less time with their families (McNeely and Blanchard, 2010, Christie and Viner, 2005). Peer relationships are significant for identity development and influence values, attitudes, behaviors, interests, sexual identity and formation of more intimate friendships including romantic relationships (McNeely and Blanchard, 2010). Peer relationships also have significant implications for adjustment during adolescence with positive peer relations linked to psychosocial adjustment (American Psychological Association, 2002). Difficulties with peer relations, including bullying and peer rejection increase the risk of depression (Platt et al., 2013, Arseneault, 2018).

The emotional and social development of ALHIV may be severely affected by their HIV diagnosis, which may affect the self-concept, self-esteem, and social competence of ALHIV. These challenges may be exacerbated for ALHIV who experience delayed physical development as a result of HIV infection and have implications for treatment engagement. In a systematic review on the mental health challenges faced by ALHIV, Vreeman et al. (2017) found that ALHIV living in resource limited settings face unique mental, emotional and behavioral health challenges linked to their biopsychosocial experiences.

Sexual development

Given a primary route for transmission is sexual activity, this stage of development is particularly helpful to understanding the needs of adolescents. Sexual development among adolescents is influenced by physical and cognitive changes and social expectations, with experiences varying across adolescence (McNeely and Blanchard, 2010). Sexual development includes the development of a sexual identity, which refers to an individual's gender, sexual orientation and interest in sexual behavior (McNeely and Blanchard, 2010). Adolescents may also begin to explore their developing sexual identities through experimentation, romantic friendships and dating (McNeely and Blanchard, 2010). Motivation to engage in sexual behavior may include biological and hormonal urges, curiosity, and a desire for social acceptance (McNeely and Blanchard, 2010). However engagement in sexual activity varies and may depend on family standards, internalized norms, opportunity, personal readiness and peer pressure (McNeely and Blanchard, 2010). Engagement in sexual activity also increases risks of onward transmission of HIV or re-infection among ALHIV.

1.5.1 Stages of adolescent development

The changes described above occur at different stages and times during adolescence with adolescent development conceptually divided into three different phases, early (11-13), middle (14-17) and late (17-19) (Salmela-Aro, 2011). The breakdown of age varies across the literature, and research has shown that the changes experienced during adolescence continue into young adulthood with some psychological research suggesting changes in the brain continue until the mid-twenties (Salmela-Aro, 2011, McNeely and Blanchard, 2010). Each phase is characterized by specific biological, psychological and social changes (Suris et al., 2004).

Early Adolescence

This stage is characterized by the onset of puberty. Individuals in this stage often have trouble regulating their emotions (Salmela-Aro, 2011). Risk-taking increases during this stage (Salmela-Aro, 2011) and adolescents tend to be more short-sighted in their thinking, often not considering the long-term consequences of their actions (McNeely and Blanchard, 2010). During this stage the importance of peers rapidly increases, and adolescents become increasingly concerned with their social status within their peer group (Salmela-Aro, 2011), with adolescents often altering their behavior to fit in (McNeely and Blanchard, 2010). Adolescents generally begin spending an increasing amount of time with their peers and less time with their family (Salmela-Aro, 2011, Close and Rigamonti, 2006) as they become more independent and relations with peers grow in importance.

Middle Adolescence

As girls often begin puberty before boys, at this stage most girls have finished experiencing the physical changes associated with puberty unlike some boys that continue developing into middle adolescence (Salmela-Aro, 2011). During this stage adolescents begin developing their individual identity, including a unique personality and opinions and developing a code of ethics (Salmela-Aro, 2011). Peers, especially friends play a significant role in the formation of their social identity and adolescents are especially involved in creating and maintaining their identity with their peers (Salmela-Aro, 2011). Compared to early and late adolescence, middle adolescents are most influenced by their peers (Salmela-Aro, 2011). The importance of romantic peers also increases in this stage and adolescents continue developing their emotional intelligence (Salmela-Aro, 2011). Cognitively, during this stage adolescents develop their abstract thinking skills and experience increases in their perception, control and planning processes (Salmela-Aro, 2011). This enables them to begin developing their thinking about the world, their place in it and planning for the future (Salmela-Aro, 2011). Risk taking behaviors also tend to peak during this stage (McNeely and

Blanchard, 2010), with adolescents beginning to use or abuse substances e.g. drugs and/or alcohol (Salmela-Aro, 2011). During this stage, interest in romantic and sexual relationships increase (McNeely and Blanchard, 2010) and sexual behavior is usually explorative with varying engagement in sexual activity (McNeely and Blanchard, 2010).

Late Adolescence

As adolescents in this stage are on the brink of adulthood, they have developed a more solid identity, stable interests, are better able to regulate their emotions and show greater concern for others (Salmela-Aro, 2011). Late adolescents have more developed self-concepts and begin to feel more comfortable in their own skin (Salmela-Aro, 2011, Close and Rigamonti, 2006). They have a more diversified peer network, begin developing more serious intimate friendships including romantic relationships (McNeely and Blanchard, 2010) and have a clear sexual identity (Salmela-Aro, 2011). During late adolescence executive and self-regulatory skills continue to develop which enhance the abilities of adolescents to weigh up the short and long-term costs of decisions and to seriously think about the future e.g. making career decisions (Reavley et al., 2017, Salmela-Aro, 2011). Late adolescents are also better able to make independent decisions and are increasingly self-reliant (Salmela-Aro, 2011).

Limitations of stage theories of adolescence

Adolescent developmental stage theories are limited as the changes described may not reflect the experiences and realities of all adolescents as the developmental changes experienced during adolescence occur at different times across the stages and may also differ across cultures based on differing social and cultural expectations, including roles and responsibilities (Salmela-Aro, 2011, Christie and Viner, 2005). Additionally, much of the literature on adolescence is based on adolescents in higher income countries whose realities and associated experiences may differ from those of adolescents growing up in resource-limited settings. Therefore attention must be given to the context, including the socio-cultural and personal factors that influence the experiences of adolescents between childhood and adulthood. However, stage theories of adolescence are helpful in examining this unique period of development and considerations of how it might affect health-related experiences.

1.6 Understanding the needs of ALHIV: a life course approach

As described above, adolescence is a key stage of the life course in which individuals experience unique biological, cognitive, emotional and social challenges however, stage theories of adolescence are limited in their scope to understand the experiences and complex realities of adolescents, especially ALHIV in resource limited settings. Alternatively, the life course approach is a multidisciplinary approach influenced by developmental and socio-cultural perspectives that takes a more holistic perspective to examining the experiences of individuals. The life course approach argues that an individual's current health status is determined by a wide range of factors within their social and historical context and is concerned with examining the impact of exposures/factors over time and during key developmental stages in the lifespan of an individual or cohort (e.g. childhood, adolescence, adulthood) that shape health and wellbeing (Nicolau et al., 2007, Hoskins and Varney, 2015, Hutchison, 2010, Braveman and Barclay, 2009).

The developmental perspective highlights the influence of early life experiences and key stages of development (e.g. adolescence) across an individual's lifetime with interest in cumulative effects (Jones et al., 2019b, Hutchison, 2011) and the socio-structural perspective takes a more ecological approach, focusing attention on the role of context, including both the social and physical contexts in which individuals live and grow and the identification of risk and protective factors (Hoskins and Varney, 2015, Hendricks, 2012, Hutchison, 2011). The approach examines the influence and interrelations between biological, social, behavioral and environmental factors across an individual's life span on their health and wellbeing (Braveman and Barclay, 2009) and is useful for examining the lived experiences of ALHIV.

In its application in the literature, the life course approach has been largely applied to studying how experiences during gestation, childhood and adolescence shape disease risk in adulthood (Braveman and Barclay, 2009, Kuh et al., 2003, Hutchison, 2011) and has been applied to the study of a variety of chronic conditions (Non et al., 2014, Lunyera et al., 2020, Docherty et al., 2015). It has contributed to important findings regarding the adaptability of risk factors and the prevention of non-communicable diseases (Mikkelsen et al., 2019, Kellam and Van Horn, 1997). A study examining associations between childhood social disadvantage and cardiometabolic function and chronic disease found that high levels of social disadvantage in childhood were significantly associated with increased cardiometabolic risk and an increased number of chronic diseases in adulthood (Non et al., 2014). It has also been applied to the study of other health concerns including general health and wellbeing, infectious disease and sexual and reproductive health (Nicolau et al., 2007, Ramsay et al., 2018, Lee, 2019, Saleem and Bhattacharya, 2021, Gray and McDonald, 2010).

The perspective is also helpful in examining health disparities (Hargrove and Brown, 2015, Kahn and Fazio, 2005, Glymour et al., 2008). For example, a study by Glymour et al. (2008) found that social conditions during childhood predicted stroke risk amongst white and black American adults and that adjustment for adult SES eliminated the disparity in stroke risk. The application of the approach to the study of various health conditions demonstrates the usefulness of the life course approach for studying health behavior and outcomes as it considers the effect of wider determinants on individual health over time and specifically considers how changes over time influence health outcomes (Rashbrook, 2019).

Regarding HIV/AIDS, many of the studies applying a life course approach examine vulnerability to HIV infection among certain populations including adults and adolescents (Mojola et al., 2015, Ruark et al., 2016, Taggart et al., 2020, Dangerfield et al., 2018, Johnson et al., 2021). For example, Mojola et al. (2015) used the approach to examine life course factors influencing HIV vulnerability among middle and older aged adults (between the ages of 40 and 80) in South Africa and found that numerous contextual, life course and individual factors increased the HIV risk among older adults. Ruark et al. (2016) used the approach to explore sexual partnerships and HIV-related risk of women and men throughout adolescence, their twenties and thirties in Swaziland and found that participants experienced various risks including multiple and concurrent partnerships, harmful social norms, violence and lack of mutual relationship trust. Other studies using the approach have examined the experiences of adults living with HIV (Wallach and Brotman, 2018, Rosenfeld et al., 2016, Moore et al., 2019). For example, Wallach and Brotman (2017) examined the challenges faced by older adults living with HIV within their intimate relationships and sexual lives as they age and found that erectile changes, difficulty using condoms, HIV and age-related stigma, changes in appearance due to HIV and aging and lower sexual desire were challenges experienced by this population.

These studies demonstrate that various social, contextual and behavioral factors influence vulnerability to HIV and the lived experiences of PLWH. However, there is a paucity of studies utilizing a life course approach to examine the lived experiences of PLWH in Africa, especially ALHIV. Adolescents have unique needs compared to younger children and adults, and it is important to explore the experiences of individuals in this dynamic life stage as they experience various unique biological, physical and social changes and challenges. The research in this thesis focuses on the critical life stage of adolescence, examining the psychosocial factors influencing the lived experiences of ALHIV and their engagement in treatment and care. Therefore, the approach is useful for considering the effects of personal experiences, key events, transitions and other important socio-contextual factors shaping the health and wellbeing of ALHIV.

Socio-cultural context and adolescent risk of HIV infection

As described in the previous section, it is important to understand the socio-cultural context surrounding adolescent HIV. In SSA adolescent girls are disproportionately affected by the HIV epidemic and in 2019 four times as many adolescent girls were newly infected with HIV compared to adolescent boys (United Nations Children's Fund, 2020). The timing of infection is also affected by gender with adolescent girls in east and southern Africa infected on average 5 to 7 years earlier than boys (The Lancet Child & Adolescent Health, 2018). Economic, social, and cultural factors play a role in the increased burden of HIV among girls in the region (The Lancet Child & Adolescent Health, 2018, Richardson et al., 2014). For instance, gender inequality and discrimination increase the vulnerability of women to HIV in SSA through the promotion of harmful gender norms, which generally expect women to be submissive and encourage men to be dominant (Burgess and Campbell, 2014). This often places women in low socio-economic positions or positions of dependence which increases their vulnerability to HIV, e.g. women are less able to access resources and negotiate safe sexual practices (Sia et al., 2016). Inter-generational relationships is another factor that increases the vulnerability of young women in SSA to HIV because HIV prevalence increases with age therefore, older partners of young women are more likely to be infected with HIV (Dellar et al., 2015). In addition, women often enter into transactional sex relationships with men due to poverty or economic instability but also to gain financial or social capital, material goods and other benefits (Harrison et al., 2015, Dellar et al., 2015, Ramjee and Daniels, 2013, Population Reference Bureau, 2002). Violence against women is another factor that increases the vulnerability of girls to HIV as violence or the fear of it can affect the ability of girls to access HIV and sexual and reproductive health services (SRH), negotiate safer sex and disclose their status to their partners, family or health care providers (Joint United Nations Programme on HIV and AIDS, 2019). These factors are compounded by the fact that women are also biologically more susceptible to getting HIV than men. Physiologically, sexual transmission of the virus is more efficient from men to women as a greater surface area of the mucosal membrane is exposed to infectious fluid, with younger women even more susceptible due to their underdeveloped cervix (Dellar et al., 2015, Population Reference Bureau, 2002, Ramjee and Daniels, 2013).

1.7 Lived experiences of ALHIV

As described above, adolescents in resource limited and high HIV burden countries face increased risk of HIV infection as a result of the socio-cultural context. It is important that the lived experiences of ALHIV are also understood in light of these challenges as the socio-ecological environment significantly affects their experiences and increases their risk of experiencing poor health outcomes. The concept of lived experience originates from phenomenology, which is a discipline that is concerned with understanding the human experience of phenomena (Smith, 2008, Finlay, 2011). In the health literature, lived experience research focuses on the perspectives and experiences of individuals with experience and/or living with an illness of interest, and has been applied to the study of various health conditions (see 4.2). The study of lived experiences is important because it can provide valuable information on the perspectives and response of individuals to their experiences (Given, 2008) that can be used to improve care provision and health outcomes. The literature on the lived experiences of ALHIV in SSA is largely based on experiences of those perinatally infected with HIV. It highlights various experiences and challenges ALHIV face navigating their lives, including learning their HIV status, coping and other psychosocial issues and experiences with HIV treatment and care. It is important that the perspectives of ALHIV are examined in order to better understand their lived experiences to improve their engagement with care. In the following sections I discuss some of the important themes represented within literature on the experiences of ALHIV in SSA.

1.7.1 Experiences surrounding disclosure of HIV status

Many vertically infected ALHIV experience prolonged bouts of illness before they are diagnosed with HIV and initiating ART (Denison et al., 2015, Daniel, 2015, Madiba and Mokgatle, 2016, Bernays et al., 2015). Many also discover their HIV status within the health care setting, with their HIV status disclosed by counselors and physicians rather than caregivers in the home (Daniel, 2015, Okawa et al., 2017, Mutumba et al., 2015b). Disclosure of HIV status is also largely reported in the literature as occurring as a one-time event rather than a process as suggested by disclosure guidelines (Maseko and Madiba, 2020, World Health Organization, 2011).

The literature concerning reactions to disclosure highlight the complex nature of the experience, with ALHIV experiencing diverse positive and negative emotions. ALHIV have described feelings of shock and disbelief upon disclosure (Madiba and Mokgatle, 2016, Okawa et al., 2017, Mutumba et al., 2015b), as they never imagined having HIV. ALHIV also describe feelings of confusion (Madiba and Mokgatle, 2016, Willis et al., 2018), particularly concerning how they were infected with HIV. They also report feelings of anger, often towards their caregivers for not disclosing their status sooner, with some expressing that it would have facilitated acceptance (Li et al., 2010b, Madiba and Mokgatle, 2016, Mutumba et al., 2015b, Gitahi et al., 2020). In addition, feelings of sadness (Willis et al., 2018, Abubakar et al., 2016) and worry, especially concerning their future (Mutumba et al., 2015b, Gitahi et al., 2020). Fear concerning what would happen to them (Li et al., 2010b, Mutumba et al., 2015b, Maseko and Madiba, 2020), including fears of death (Madiba and Mokgatle, 2016, Ashaba et al., 2019, Okawa et al., 2017, Doat et al., 2021) are also commonly reported in the literature. ALHIV also feel hopelessness (Ashaba et al., 2019, Mutumba et al., 2015b, Doat et al., 2021, Gitahi et al., 2020), with some expressing wanting to commit suicide as they felt hopeless and/or distressed (Li et al., 2010b, Abubakar et al., 2016, Okawa et al., 2017, Mutumba et al., 2015b, Doat et al., 2021). They also report feeling different from their siblings and peers because they are living with HIV and the impact of the HIV diagnosis on their lives (Mutumba et al., 2015b, Willis et al., 2018, Petersen et al., 2010, Maseko and Madiba, 2020). Many also report isolating themselves and withdrawing from family and friends (Mutumba et al., 2015b, Willis et al., 2018, Petersen et al., 2010).

Few positive emotions have been reported and these include relief and happiness at learning the cause of their illness (Madiba and Mokgatle, 2016, Mutumba et al., 2015b, Maseko and Madiba, 2020), which enabled adolescents to understand why they were ill and seek treatment to get better. Neutral reactions have also been reported, with ALHIV reporting not knowing and/or understanding what it meant to be HIV positive at the time of disclosure (Mutumba et al., 2015b, Madiba and Mokgatle, 2016).

1.7.2 Coping with HIV status disclosure

As described above, learning of HIV status is a significant life-changing experience in the lives of ALHIV which has implications for their health and wellbeing. Understanding how ALHIV cope with their HIV diagnosis is important because the literature on coping with HIV demonstrates that the manner in which a person living with HIV copes affects their ability to handle the stresses related to navigating life living with HIV (Fife et al., 2008) and the types of strategies used to cope with chronic disease also has implications for adjustment and long-term wellbeing (Varni et al., 2012, Fife et al., 2008). Understanding these experiences of coping can also inform practice and the development of interventions targeting ALHIV (Orban et al., 2010).

Coping strategies can be conceptualized as emotion focused or problem focused (Lazarus and Folkman, 1984). Emotion focused strategies used to cope with HIV diagnosis among ALHIV include acceptance, with adolescents emphasizing the incurable nature of HIV (Madiba and Mokgatle, 2016, Mutumba et al., 2015a, Maseko and Madiba, 2020); rationalization and comparison, with ALHIV describing that they are no different from adolescents living without HIV (Madiba and Mokgatle, 2016, Mutumba et al., 2015a, Maseko and Madiba, 2020);

religion/spirituality, with ALHIV reporting that prayer gives them strength to persevere in their everyday life (Mutumba et al., 2015a, Ashaba et al., 2019, Li et al., 2010b, Midtbø et al., 2012, Daniel, 2015) and treatment confidence, with ALHIV reporting that ART will improve their health and wellbeing (Mutumba et al., 2015a, Petersen et al., 2010). Social support is a significant emotion focused strategy used by ALHIV, and ALHIV describe receiving support from family (Ashaba et al., 2019, Petersen et al., 2010, Crowley et al., 2019, Hodgson et al., 2012, Li et al., 2010b), friends (Petersen et al., 2010, Hodgson et al., 2012, Li et al., 2010b, Mutumba et al., 2015a), peer support groups (Petersen et al., 2010, Hodgson et al., 2012, Midtbø et al., 2012, Gitahi et al., 2020) and health care workers (Mutumba et al., 2015a, Li et al., 2010b, Ashaba et al., 2019).

1.7.3 Diverse psychosocial challenges experienced by ALHIV

In addition to the difficulties of becoming aware of and coping with an HIV diagnosis, ALHIV face other significant psychosocial challenges including parental loss, mental health challenges, HIV-related stigma, and disclosure of HIV status. Parental loss is a significant emotional challenge faced by many ALHIV in SSA and significantly affects their psychosocial wellbeing (Petersen et al., 2010, Willis et al., 2018, Ashaba et al., 2019, Oladunni et al., 2021, Maseko and Madiba, 2020). Studies indicate that ALHIV who have experienced parental loss report psychological distress, low self-esteem, poor social support and socio-economic challenges (Ashaba et al., 2019, Willis et al., 2018, Oladunni et al., 2021).

As described earlier, mental health challenges increase during adolescence (Salmela-Aro, 2011), however, ALHIV are at increased risk of experiencing such challenges including depression and anxiety compared to adolescents not living with HIV (Toska et al., 2019, Okawa et al., 2018b, Madiba and Mokgatle, 2016, Vreeman et al., 2017, Too et al., 2021). A systematic review by Vreeman et al. (2017) assessing mental health challenges faced by ALHIV in developing and developed countries found high rates of depressive symptoms among ALHIV in low and middle income countries. Contextual challenges faced by ALHIV in resource limited settings increase their risk of developing psychological problems, including poverty, parental loss, lack of social support, lack of educational opportunities, and HIV-related stigma (Mavhu et al., 2013, Mthiyane et al., 2021, Vreeman et al., 2017, Dessauvagie et al., 2020). The experience of psychological problems has also been linked to poor adherence among ALHIV (Hudelson and Cluver, 2015, Laurenzi et al., 2020, Kim et al., 2014). However, mental health services are very limited in SSA (Wogrin et al., 2021, Vreeman et al., 2017).

ALHIV also struggle with internalized stigma, including feelings of discomfort (Petersen et al., 2010), devaluation (Kimera et al., 2020b) guilt and/or shame due to negative beliefs surrounding HIV in their communities (Doat et al., 2021). For example, a study in Ghana found that ALHIV experienced shame due to widely held beliefs that HIV is a punishment from God (Doat et al., 2021). HIV-related stigma also increases risks of experiencing depression and anxiety among ALHIV (Vreeman et al., 2017). These mental health challenges experienced by ALHIV are associated with poor engagement with HIV care services, including adherence to ART (Too et al., 2021, Vreeman et al., 2017).

Furthermore, self-disclosure of HIV status is another significant stressor highlighted in the literature. As a result of the highly stigmatized nature of HIV in SSA many ALHIV feel that their HIV status should be kept a secret (Denison et al., 2015, Madiba and Mokgatle, 2016, Abubakar et al., 2016) with many choosing to not disclose their HIV status beyond their immediate family (Hodgson et al., 2012, Petersen et al., 2010, Midtbø et al., 2012). HIV-related stigma and discrimination is a significant barrier to onward disclosure of HIV status in this population (Li et al., 2010b, Midtbø et al., 2012, Petersen et al., 2010, Mutumba et al., 2015a, Maseko and Madiba, 2020).

ALHIV are especially hesitant to disclose their HIV status to their peers, including friends and romantic and/or sexual partners as they fear negative consequences including rejection, isolation and/or lack skills to disclose their status to sexual partners (Bakeera-Kitaka et al., 2008, McCarraher et al., 2018, Madiba and Mokgatle, 2016). Consequences of self-disclosure vary and include both positive and negative reactions (Li et al., 2010b, Midtbø et al., 2012, Madiba and Mokgatle, 2016, Petersen et al., 2010, Crowley et al., 2019). However, there is very little literature concerning the motivations and facilitators of self-disclosure among ALHIV in SSA. HIV-related stigma is also reported as a significant barrier to engagement with HIV care in the literature (van Wyk and Davids, 2019, Audi et al., 2021) and is further described in the next section.

1.7.4 Adolescent experiences with engagement across the HIV care continuum

As described above, ALHIV experience various challenges that have implications for their engagement in HIV treatment and care. The HIV care continuum is a conceptual framework that outlines the steps involved in treating and caring for individuals living with HIV (Kay et al., 2016). These key steps include: HIV testing, linkage to care, retention in care, adherence to ART and viral suppression (Kay et al., 2016). ALHIV have been found to have poor outcomes across this continuum (Figure 1-2) which are discussed in the following sections.

Figure 1-2: HIV Care Continuum

HIV Testing

HIV testing is the first step in the continuum of care for PLWH, yet many adolescents are unaware of their HIV status, with the burden of undiagnosed HIV higher in children and adolescents than adults (Govindasamy et al., 2015). Survey data collected between 2005 and 2015 in SSA found that only 10% of men and 15% of women aged 15-24 knew their HIV status (World Health Organization, 2013b). Another study among adolescents aged 15-19 found that only 19% of adolescent girls and 14% of adolescent boys in eastern and southern Africa had been tested for HIV and received their results in the last 12 months (The United Nations Children's Fund, 2019). Despite the disproportionate burden of HIV among adolescent girls, only 1 in 5 adolescent girls living with HIV are aware of their HIV status (Wong et al., 2017). The low rates of testing among adolescent girls is worrisome as the fertility rate among young women is high in the region, e.g. more than half of the births in Sub-Saharan Africa occur during adolescence, especially among girls aged 15-19 (Callahan et al., 2017).

Barriers to HIV testing reported from studies with adolescents in SSA include low perception of personal risk; lack of HIV/AIDS knowledge; HIV-related stigma; lack of youth friendly health services; concerns over confidentiality and legal barriers such as age of consent and parental consent laws (Sam-Agudu et al., 2016, Strauss et al., 2015, Aluzimbi et al., 2017, Qiao et al., 2018, Williams et al., 2017). It is crucial that existing barriers to HIV testing are addressed as awareness of HIV status is crucial to improve engagement with care and treatment outcomes among ALHIV as several studies have shown that low HIV testing rates and late diagnosis of HIV are associated with increased HIV-related mortality and morbidity (Belay et al., 2017, Anglemyer et al., 2014, Auld et al., 2014).

Linkage to care, retention in treatment, adherence to ART and viral suppression

Findings from the literature indicate that ALHIV in SSA experience several challenges along these four later stages of the care continuum. For example, ALHIV have poorer HIV treatment outcomes compared to adults, including poorer adherence and virologic outcomes (van Wyk and Davids, 2019, Nachega et al., 2009). Some of the reported barriers to enrollment/linkage to care among ALHIV include inadequate counselling (Luseno et al., 2017); inaccurate knowledge and negative perceptions of treatment (Williams et al., 2017, Luseno et al., 2017). Facilitators of linkage to care include testing for HIV during hospitalization or treatment (Luseno et al., 2017); initiating treatment immediately or shortly after diagnosis (Luseno et al., 2017) and support from family and health care workers (Luseno et al., 2017).

Poor adherence to ART is a significant concern among ALHIV and identified barriers to adherence include lack of awareness about HIV status (Kawuma et al., 2014, Denison et al., 2015); psychological distress and depression (Okawa et al., 2018b, Kim et al., 2017, Ankrah et al., 2016, Mutumba et al., 2016, World Health Organization, 2013a); medication side effects (Okawa et al., 2018b, Denison et al., 2015, Kawuma et al., 2014, Ankrah et al., 2016); lack of HIV and/or HIV treatment knowledge (Okawa et al., 2018b, Mutumba et al., 2019); poor treatment self-efficacy (Kim et al., 2017, Okawa et al., 2018b); forgetfulness (Ankrah et al., 2016, Falcão et al., 2021, Tunje et al., 2021); burden of adherence (Denison et al., 2015, Mutumba et al., 2015a, Luseno et al., 2017); cost of transportation to clinic (Ankrah et al., 2016, Maskew et al., 2016); HIV-related stigma (Kim et al., 2017, Carbone et al., 2019), including the fear of unintentional disclosure (Ashaba et al., 2019, Willis et al., 2018, Kim et al., 2017, Kawuma et al., 2014, Mutumba et al., 2019, Carbone et al., 2019); and adolescent daily life schedules and/or activities (Denison et al., 2015, Okawa et al., 2018b, Kim et al., 2017, Kawuma et al., 2014). Adherence has also been found to be especially problematic for adolescents attending boarding school (Mutumba et al., 2019, Ashaba et al., 2019, Mutumba et al., 2015a).

Poor adherence to ART among ALHIV contributes to treatment failure which is problematic because access to more advanced ART regimens is limited in resource limited settings (Chimbetete et al., 2020, Burns et al., 2019), including in Zambia as descried earlier. Despite increasing numbers of ALHIV failing on first line ART little is known about the experiences of ALHIV on second and third line regimens. Facilitators of adherence to ART include awareness of HIV status (Midtbø et al., 2012, Okawa et al., 2017, Cluver et al., 2015, Biadgilign et al., 2009, Gitahi et al., 2020); wanting to be healthy/stay well (Denison et al., 2015, Madiba and Mokgatle, 2016, Ankrah et al., 2016, Bernays et al., 2015) and emotional and instrumental support (Denison et al., 2015, Crowley et al., 2019, Daniel, 2015, Ankrah et al., 2016, Ashaba et al., 2019).

Barriers to retention in care among ALHIV in SSA include school attendance (Enane et al., 2020, Toska et al., 2019); distance to clinics and transportation costs (Enane et al., 2020, Petersen et al., 2010, Abubakar et al., 2016, Maskew et al., 2016, Madiba and Josiah, 2019); long queues and/or waiting time at clinic (Ritchwood et al., 2020, Hodgson et al., 2012, Maskew et al., 2016, Luseno et al., 2017); medication side effects (Luseno et al., 2017); lack of YFHS (World Health Organization, 2013a); poor relationships with health care workers (Hodgson et al., 2012, Enane et al., 2020, Ritchwood et al., 2020, World Health Organization, 2013a, Zanoni et al., 2019); anxiety and/or depression (World Health Organization, 2013a); HIV-related stigma (St Clair-Sullivan et al., 2019, Williams et al., 2017) and fear of disclosure of HIV status (Luseno et al., 2017, Zanoni et al., 2019). Facilitators of retention in care include support from family and friends (Tunje et al., 2021); youth/adolescent friendly services (Zanoni et al., 2019); good relationships with health staff (Zanoni et al., 2019, World Health Organization, 2013a, Tunje et al., 2021); and treatment confidence (Tunje et al., 2021).

These barriers to engagement with HIV care contribute to poor treatment outcomes among ALHIV including poor adherence (Nachega et al., 2009, Kim et al., 2017, Filho et al., 2008, Ammon et al., 2018, Adejumo et al., 2015, Hudelson and Cluver, 2015), low rates of virologic suppression (Nachega et al., 2009, Evans et al., 2013, Ryscavage et al., 2011), high rates of viral rebound (Nachega et al., 2009, Ryscavage et al., 2011), high rates of loss to follow up (Evans et al., 2013, Ryscavage et al., 2011, Auld et al., 2014) and poor mental health outcomes, including high rates of depression (Woollett et al., 2017, Kim et al., 2015, Dow et al., 2016, Kemigisha, 2018).

Transition to adult HIV care

The transition from pediatric to adult care is an important experience in the life course of ALHIV, especially perinatally infected adolescents, that has significant implications for treatment engagement. During this time ALHIV are at increased risk of experiencing poor HIV treatment outcomes, including poor adherence (Kakkar et al., 2016), low rates of retention (Ryscavage et al., 2016, Zanoni et al., 2020, Agwu et al., 2015) and virologic suppression (Ryscavage et al., 2011), high rates of viral rebound (Ryscavage et al., 2011) and increased mortality (Kakkar et al., 2016, Fish et al., 2014).

Very few studies in SSA have explored the outcomes of transition to care among ALHIV (Dahourou et al., 2017). However, few studies examining the experiences of ALHIV highlight the manner of transition (e.g. abrupt/sudden) (Masese et al., 2019, Abaka and Nutor, 2021); lack of preparation for transition (Abaka and Nutor, 2021, Masese et al., 2019); emotional and interpersonal burdens associated with transition (Jones et al., 2019a); difficulty navigating adult clinics (Kung et al., 2016, Katusiime et al., 2013); effects of HIV disease (e.g. cognitive delay) (Kung et al., 2016); unfavorable adult clinic days (Masese et al., 2019); differences in the quality of care provided (Masese et al., 2019); HIV-related stigma (Masese et al., 2019, Katusiime et al., 2013, Kung et al., 2016); lack and/or poor communication with health care workers (World Health Organization, 2013a); and poor evaluation of adolescent abilities and capacities related to treatment self-efficacy (World Health Organization, 2013a) as barriers to successful transition.

Despite these barriers that increase the likelihood of poor engagement and treatment outcomes post-transition to adult care, many low and middle income countries lack national guidelines on the transition of adolescents to adult HIV care services (Jones et al., 2019a, Dahourou et al., 2017). There is also a lack of structured transition protocols in health facilities, resulting in disorganized transition processes with practices differing within various health facilities (Abaka and Nutor, 2021, Woollett et al., 2021). This is also the case in Zambia, where interview findings highlighted an unstructured process to transition of care. Understanding the factors affecting access and engagement with HIV treatment and care across the HIV care continuum among ALHIV in high HIV burden resource-limited settings is crucial to improving engagement with HIV care and treatment and improving the health and wellbeing of ALHIV.

1.8 Addressing gaps in the literature on the experiences of ALHIV: Thesis aims

The review of the literature above demonstrates that ALHIV in SSA experience various challenges navigating living with HIV, especially concerning HIV care and treatment. However, there is a need for more in-depth qualitative studies to enhance understandings of the experiences and challenges faced by this population, building on existing qualitative work to fill existing gaps in the literature. Existing gaps in the literature include: limited literature on the experiences of adolescents along the HIV care continuum and psychosocial challenges and response of ALHIV in Zambia, limited literature on the experiences of ALHIV on second and third line ART, limited literature on perceptions and experiences with transition from pediatric to adult care, limited literature on the self-disclosure experiences of ALHIV (particularly motivations and facilitators of disclosure), lack of studies applying a life course lens to understand the experiences of ALHIV and limited literature on the perspectives and experiences of health service providers (HSPs) working with adolescents who play a key role in shaping the experiences of ALHIV along the HIV care continuum in resource limited settings.

Furthermore, many of the existing studies in the literature on the experiences of ALHIV also include youth populations and do not provide disaggregated data on the experiences of adolescents despite their unique needs, experiences and challenges (Zanoni et al., 2019, Dow et al., 2016, Hornschuh et al., 2017, St Clair-Sullivan et al., 2019, Siu et al., 2012). Better understanding the lived experiences of ALHIV, especially factors influencing their health decisions and behaviors would inform the development of targeted interventions to better support this population, especially since there is a lack of evidence-based interventions targeting this population in limited resource settings (Mutumba et al., 2015a, Petersen et al., 2010).

As such the main objective of this thesis is to contribute to the literature on the lived experiences of ALHIV, particularly understandings of the psychosocial challenges faced by this population in resource limited settings in SSA. Based on the literature presented above this thesis has the following aims:

I. Interpret barriers and facilitators to accessing and engaging in care along the HV care continuum
II. Analyze the lived experiences and psychosocial factors affecting the experiences of ALHIV
III. Propose interventions to address identified gaps and improve treatment engagement and outcomes

To address these aims I explore the experiences of adolescents using the HIV care continuum as an organizing framework. This thesis begins with a systematic review exploring the self-disclosure experiences of ALHIV in SSA. The main body of this thesis is qualitative research examining the lived experiences of ALHIV from the perspectives of adolescents and HSPs in Zambia. A socio-ecological lens is applied in interpreting the various psychosocial factors and their associated effects to contextualize and better understand the factors shaping the experiences of ALHIV in limited resource settings and to support the development of appropriate interventions to improve health outcomes in this population.

Chapter 2 Theoretical perspectives

2.1 Introduction

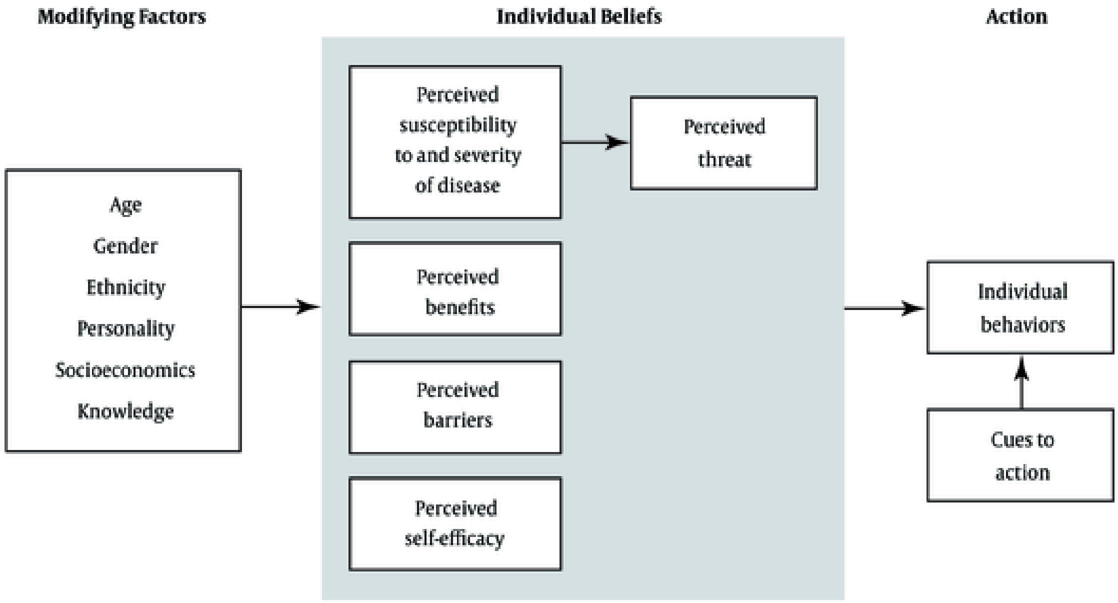
This chapter describes the theoretical framework used to guide this study of the lived experiences of ALHIV. It provides an overview of three theoretical frameworks that have been widely applied in research concerning HIV-related health behavior. The main aim of this thesis is to identify psychosocial factors influencing the lived experiences of ALHIV and affecting engagement in HIV treatment and care along the HIV care continuum, especially factors influencing health decisions and behaviors. As a result, the selected theories were chosen because of their usefulness in understanding various factors influencing health behaviors and health outcomes among populations. The theories discussed include: The Health Belief Model, The Information Motivation and Behavioral Skills model and the Socio-ecological model. This chapter describes the models and provides examples of their application in HIV/AIDS research. These theories have been widely used to explain health behavior change in relation to a variety of health conditions. In the context of HIV/AIDS, they have been applied to HIV prevention, treatment, and intervention development and amongst various populations. I argue that the Health Belief Model and the Information Motivation and Behavioral Skills model are limited in their scope to understanding the lived experiences of ALHIV and the diverse factors affecting their wellbeing because they do not consider the contribution of the socio-ecological environment which as highlighted in the previous chapter, significantly affects the experiences of adolescents. Context is very important in understanding lived experiences, health behaviors and improving health outcomes therefore, I selected the socio-ecological model to frame the research in this thesis.

2.2 The Health Belief Model

The Health Belief Model (HBM) is widely used in health behavior research to understand health decision making and focuses on the attitudes and beliefs of individuals in order to predict behavior. The model has six constructs that are used to predict whether an individual will engage in health promoting behaviors (Figure 2-1). These constructs are: *perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action and self-efficacy.*

Perceived susceptibility refers to the beliefs an individual holds about the likelihood of becoming ill and *perceived severity* refers to an individual's judgment of the severity of an illness and its consequences, e.g. clinical and social (Champion and Skinner, 2008). The combination of both perceived susceptibility and perceived severity is referred to as the perceived threat of disease (Champion and Skinner, 2008). *Perceived benefits* refers to an individual's evaluation of the benefits of engaging in actions to reduce the threat of disease; *perceived barriers* refers to the beliefs an individual holds about the barriers to engaging in a certain behavior; *cues to action* refers to events or things that push individuals to act and engage in a certain health behavior, such as experiencing migraines or a local health campaign; and *self-efficacy* refers to the beliefs an individual holds about their ability to effectively carry out the recommended health action and overcome any perceived barriers (Champion and Skinner, 2008). The self-efficacy construct was added to the HBM in the late 1980s to better account for behavior change and maintenance (Champion and Skinner, 2008). It is believed that the combination of these beliefs may lead to health behavior change. For example, if an individual perceives the threat of experiencing an illness as minimal and does not see the value of engaging in a specific behavior to reduce their risk of experiencing it and/or do not believe they have the necessary skills or knowledge to do so, they are less likely to change their behavior. The model also accounts for individual modifying factors such as age, gender, ethnicity, personality, socioeconomics and knowledge that may affect an individual's health beliefs and their cues to action (Champion and Skinner, 2008).

Figure 2-1: Health belief model[7]



The model was initially developed by a group of social psychologists in the early 1950s working with the US Public Health Service to examine factors affecting participation in Tuberculosis screening programs among a sample of adults in Boston, Cleveland and Detroit (Hochbaum, 1958, Steckler et al., 2010, Hochbaum, 1956, Champion and Skinner, 2008). They found that 82% of individuals who believed they were susceptible to contracting tuberculosis and held positive views about the benefits of early detection reported having had a chest x-ray within the 7 year period preceding the interview compared to 21% of those who did not hold such beliefs (Hochbaum, 1958, Rosenstock, 1974). The

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[7] Source: Glanz et al. (2008)

model was further developed by other social psychologists investigating utilization of health services (Rosenstock, 1974).

The model has been widely used to examine relationships between health beliefs and health behaviors and inform the development of interventions (Champion and Skinner, 2008). Among adolescents it has been applied to explain, examine and predict health behaviors and associated knowledge with a variety of health concerns and conditions including hypertension (Puspita et al., 2017); osteoporosis (Hazavehei et al., 2007, Ghaffari et al., 2012); diabetes (Bond et al., 1992); injury prevention (Kılınç and Gür, 2020, Germeni et al., 2009); food allergies (Jones et al., 2014); diet and nutrition (Szabó and Pikó, 2019, Arash et al., 2016, Ha et al., 2017, Keshani et al., 2019, Rabiei et al., 2017, Salem and Said, 2018); fertility control (Eisen et al., 1985, Yakubu et al., 2019); oral health (Xiang et al., 2020, West et al., 1993); cancer (Al-Harbi et al., 2017, Price et al., 1988); drug use (Fadaei et al., 2020); smoking (Ghaderi et al., 2016); and SARS (Wong and Tang, 2005). For example, Puspita et al. (2017) found that perceived threat, perceived benefits, self-efficacy and cues to action were directly associated with hypertension preventive behaviors among a sample of Indonesian adolescents. Results from these studies show that the HBM is useful in understanding psychological factors associated with a diverse range of health behaviors and useful for guiding the development and evaluation of interventions to improve knowledge and/or change behaviors.

With regards to HIV/AIDS the HBM has been widely used to explore adolescent perceptions of and actual HIV risk (Darteh et al., 2016, Booth et al., 1999, Aluzimbi et al., 2017, Tarkang, 2014); predict intentions of and/or engagement in HIV-related preventive behaviors, e.g. safer sex practices (White, 2004, Petosa and Jackson, 1991, Khalil et al., 2005, Lux and Petosa, 1994, Hingson et al., 1990, Walter et al., 1992, Wilson et al., 1990, Iriyama et al., 2007, Abraham et al., 1992, Khani Jeihooni et al., 2018, Thato et al., 2003, Adih and Alexander, 1999) and HIV testing uptake (Ajayi et al., 2019, Kabiru et al., 2011, Abebe and Mitikie, 2009, Schnall et al., 2015). For example, Aluzimbi et al. (2017) found that knowledge gaps (e.g. potential consequences of HIV infection), low susceptibility to infection and barriers to HIV testing (e.g. fear of parental reactions) affected HIV testing uptake among a sample of Ugandan adolescents. However, fewer studies have used the HBM to examine experiences of ALHIV (Mayeye et al., 2019, Nakigozi et al., 2015) compared to adults living with HIV. Among adults studies have explored enrollment in HIV care and/or treatment initiation (Gebru et al., 2018, Nakigozi et al., 2013), retention in treatment (Wringe et al., 2009) and adherence (Vitalis, 2017, Afe and Motunrayo, 2017, Wutoh et al., 2005, Gharlipour et al., 2018, Wringe et al., 2009). For example, Wringe et al (2009) found that perceived susceptibility, severity, barriers and self-efficacy to attend appointments were associated with regular clinic attendance among adults in Tanzania. Findings from these studies demonstrate the usefulness of the HBM in exploring HIV/AIDS-related beliefs and treatment behaviors/outcomes, e.g. adherence, retention in care, etc. among ALHIV.

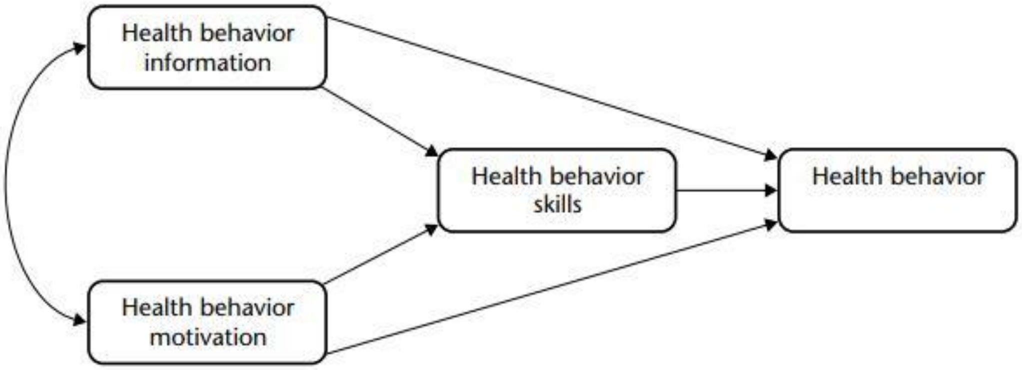
There are a few factors limiting the applicability of the HBM. For example, Norman and Conner (2017) argue that the model does not specify the relationships between constructs leading to the performance of a health behavior. This makes it difficult to know where to intervene and apply the model systematically (Glanz et al., 2008, Munro et al., 2007, Stroebe and de Wit, 1996, Norman and Conner, 2017). Secondly, the HBM assumes behavior change is the result of rational decision-making involving the consideration of benefits and barriers and does not consider other potentially important individual or personal determinants of behavior (Munro et al., 2007, LaMorte, 2019, Afe and Motunrayo, 2017). Lastly, the HBM like other cognitive focused theories of behavior change, does not consider the role of the social and environmental context in which an individual lives and functions in understanding health behavior (LaMorte, 2019, Stroebe et al., 1996, Traube et al., 2011). As noted in Chapter 1, various factors have been shown to affect health outcomes among PLWH. This is especially problematic in the context of adolescence, as important determinants of adolescent health are not considered in the HBM (Hiltabiddle, 1996). For example, Hiltabiddle (1996) argues that the model does not account for the cognitive level of adolescents in evaluating personal risks for health decision-making, emotional factors or the influence of peers in significantly influencing the perceptions and behaviors of adolescents. Therefore, the HBM is not an appropriate framework to guide this thesis, as it is concerned with understanding or explaining relationships between specific health beliefs and behaviors and is narrowly focused on individual rational decision-making processes. As social beings who both influence and are influenced by our environment, the lack of consideration of socio-environmental factors (e.g. interpersonal relationships with others), significantly affects the usefulness of the HBM in understanding the complexity of the lived experiences of ALHIV in resource limited settings, especially across the life course.

2.3 The Information Motivation and Behavioral Skills Model

The Information Motivation and Behavioral skills model (IMB) is useful for understanding engagement in health-related behaviors. It was originally created by Fisher and Fisher (1992) to explain psychological determinants of changes in AIDS-risk behavior following their review of AIDS-risk reduction intervention literature between 1980 and 1990. This review of the AIDS-risk reduction literature included empirical work that involved diverse populations, including homosexual/bisexual men; adolescents; university students; intravenous drug users; patients at STD clinics; female sex workers and the general public (Fisher and Fisher, 1992).

In their review, Fisher and Fisher (1992) identified three constructs that are believed to be fundamental determinants of AIDS-risk reduction: information, motivation and behavioral skills. The model assumes that these three fundamental determinants are important for the performance of health-related behaviors (Figure 2-2). *Information* refers to information about the health behavior and includes facts; simple rules that help individuals make quick decisions which are often incorrect and implicit theories, which are complicated sets of beliefs that are also often incorrect (Fisher et al., 2003, p. 84). *Motivation* refers to the inclination to perform health behaviors and is influenced by both personal and social motivation (Fisher et al., 2003). Personal motivation refers to an individual's attitude towards the health-related behavior and social motivation refers to perceived social norms or social support for the behavior (Fisher et al., 2003). Lastly, *behavioral skills* refers to the possession of the necessary skills and self-efficacy to carry out the health-related behavior (Fisher et al., 2003). Causal relationships exist between these constructs, with health-related information and motivation primarily influencing the performance of health-related behaviors through behavioral skills (Fisher et al., 2003). For example, if an individual is well informed, motivated to act and has the skills necessary to engage in a particular health behavior they are likely to perform or maintain that behavior and experience positive health outcomes (Fisher et al., 2003). The model also suggests that information and motivation may directly affect the performance of health-related behavior, e.g. when the behavior is relatively simple to carry out (Fisher et al., 2003).

Figure 2-2: Information Motivation and Behavioral skills model[8]



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[8] Source: Fisher et al. (2003)

The IMB model is highly generalizable and has been applied to explain and promote a variety of health-related behaviors (Fisher et al., 2003). For example, in the adolescent literature it has been used to examine determinants of and explain dietary behaviors (Fleary et al., 2020, Kelly et al., 2012, Daly et al., 2016); lifestyle choices (Tajik et al., 2020, Molaifard et al., 2018, Zhu et al., 2013); diabetes management (Bakir et al., 2020, Lee et al., 2019, Rajkumar et al., 2015) and online safety (Popovac and Fine, 2018). For example, Lee et al. (2019) found that self-efficacy and social support from family were significant predictors of diabetes self-management among South Korean adolescents. Due to its origin the IMB model has been widely used in understanding HIV preventive behaviors among adolescents. For instance, it has been used to assess determinants of risky and explain engagement in risky and/or preventive HIV behaviors (Morrison-Beedy et al., 2003, Robertson et al., 2006, Kalichman et al., 2002, Maticka-Tyndale and Tenkorang, 2010, Mustanski et al., 2006, Donenberg et al., 2005, Ybarra et al., 2013) and in the development and evaluation of interventions to increase uptake of HIV-preventive behaviors (Lemieux et al., 2008, Ndebele et al., 2012, Hong et al., 2010, Espada et al., 2015, Malow et al., 2009).

However, its application among ALHIV is very limited. For example, it has been applied to examine determinants of ART adherence (Hawkins et al., 2016, Whiteley et al., 2018) and assess engagement in sexual risk behaviors (Bakeera-Kitaka et al., 2008, Marhefka et al., 2011). For example, Bakeera-Kitaka et al. (2008) found that Ugandan young people including adolescents had gaps in SRH and HIV knowledge and were motivated to protect themselves from the consequences of sexual risk but faced multiple barriers to engaging in preventive behaviors, e.g. peer pressure, HIV-related stigma, alcohol use, etc. It has been more widely applied among adults living with HIV. For example, it has been applied to examine determinants of ART adherence (Amico et al., 2005, Peltzer et al., 2010, Starace et al., 2006, Kalichman et al., 2001, Horvath et al., 2014), engagement with treatment/retention in care (Graham et al., 2018, Konkle-Parker et al., 2014, Smith et al., 2018) and in risk reduction behaviors (Kiene et al., 2013, Nostlinger et al., 2011, Fisher et al., 2014). The literature demonstrates that the model has been successfully applied in diverse populations and in both high and low resource settings and suggests that the IBM model may be useful in identifying and understanding factors affecting HIV-related health behaviors among ALHIV and the development of targeted interventions for this population.

Additionally, the IMB model has three important strengths compared to the HBM. Firstly, the model integrates crucial constructs and ideas from widely applied social and health psychology theories in the field of health promotion, e.g. the HBM, Theory of Reasoned Action/Theory of Planned Behavior, and Social Cognitive Theory (Fisher et al., 2003). Secondly, it outlines the relationships between its constructs, facilitating the testing of the model and the development of health promotion interventions (Fisher et al., 2003). Lastly, the IMB model considers the impact of social influences, e.g. social norms and inter-personal relationships e.g. social support, through the construct of motivation. As described earlier in this thesis (Chapter 1) social influences, especially that of peers significantly affect adolescent behavior. The influence of social support on adolescent engagement in health promoting behaviors is demonstrated in the evidence from some of the studies cited above. For example, social support from family and peers affects fruit and vegetable intake (Kelly et al., 2012) and diabetes management (Lee et al., 2019, Bakir et al., 2020) and perceived peer support of HIV-preventive behaviors affects engagement in risky behaviors (Boyer et al., 2000, Bazargan et al., 2010, Robertson et al., 2006). Similarly, among the adult studies, social support was associated with adherence to ART (Peltzer et al., 2010, Amico et al., 2009, Graham et al., 2018).

However, being a cognitive based theory like the HBM, a major limitation of the IMB model is the exclusion of an individual’s environmental context in explaining health behavior, as the model assumes that a well informed and motivated individual has the capacity to change their behavior (Traube et al., 2011).

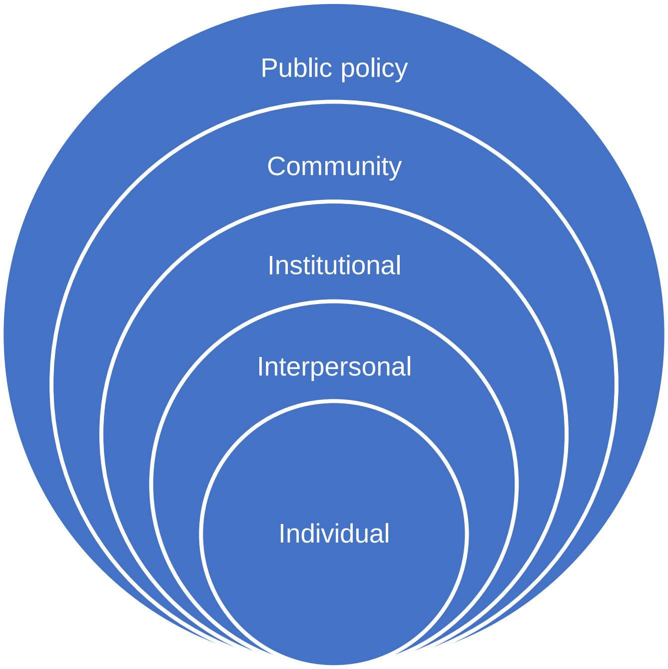
However, the health promotion literature has demonstrated that in addition to the individual determinants of behavior, environmental factors play a crucial role in the initiation and maintenance of health promoting behaviors (Yen and Syme, 1999, Sallis et al., 2006). And in the context of the IMB, such factors may also affect an individual's knowledge and motivation to engage in a health behavior. The effects of these wider social, economic, political, cultural, and environmental factors that affect the opportunities for individuals to engage in health promoting behaviors are not explored in the IMB model (Ndebele et al., 2012, Traube et al., 2011) therefore, the IMB model is not an appropriate framework to explore and contextualize the lived experiences of ALHIV, especially those living in low-resource settings that face diverse socio-economic and psychosocial challenges.

2.4 The Socio-Ecological Model

The Socio-Ecological Model (SEM) is a theory-based framework that has been widely used in the field of health promotion and calls for a more comprehensive approach to understanding health behavior. It originated from Bronfenbrenner's (1979) ecological systems theory that describes the effects of environmental influences on child development. The theory described four nested levels of environmental influences: the microsystem, mesosystem, exosystem and macrosystem. The microsystem refers to an individual's immediate environment, and includes interactions with family at home, colleagues at work and classmates and teachers at school (Bronfenbrenner, 1977). The mesosystem refers to the interrelations between an individual's microsystems, e.g. relations between school and home (Bronfenbrenner, 1979). The exosystem includes the effects of other settings or contexts in which the individual is not actively part of but that affect them, e.g. parental workplace and/or friends (Bronfenbrenner, 1979). Finally, the macrosystem encompasses the overarching systems in which the lower order systems occur within, and include social, educational, economic and political systems, e.g. cultural values and socio-economic status (Bronfenbrenner, 1979, Bronfenbrenner, 1977).

The SEM as applied to health promotion, demonstrates that health and health behaviors are influenced by multiple and interacting factors existing at various levels of society (Kilanowski, 2017). The SEM as described by McLeroy et al. (1988) identifies five levels of influence on health behavior: intrapersonal, interpersonal, institutional, community and public policy (Figure 2-3). The intrapersonal level includes individual characteristics such as attitudes, beliefs, knowledge and skills (McLeroy et al., 1988). The interpersonal level includes "formal and informal social networks and social support systems" (McLeroy et al., 1988, p. 355) such as family, friends and work groups. The institutional level includes "social institutions with organizational characteristics and formal (and informal) rules and regulations for operation" (McLeroy et al., 1988, p. 355). The community level includes "relationships among organizations, institutions, and informal networks within defined boundaries" (McLeroy et al., 1988, p. 355) and include social norms, values and standards and the social contexts in which individuals live, e.g. neighborhoods, schools, workplaces, etc. The policy level includes "local, state, and national laws and policies" (McLeroy et al., 1988, p. 355). These personal and environmental factors are interactive, interdependent and dynamic, influencing an individual's health and health behavior through a variety of complex relationships (Stokols, 1996, Michielsen et al., 2012).

Figure 2-3: Socio-ecological model[9]



The SEM highlights the wider environmental factors that influence health behaviors unlike the HBM and IMB model that emphasize individual characteristics and traits (Sallis et al., 2015). The importance of examining environmental factors to explain and predict health behavior was emphasized in the findings of some of the studies described above that reported the limited explanatory power of cognitive based models, like the HBM and IMB in accounting for health behavior (Vitalis, 2017, Donenberg et al., 2005, Thato et al., 2003, Amico et al., 2005). This once again, illustrates the limitations of cognitive behavioral models in understanding engagement in health behaviors. The SEM also allows for “cross-level analyses of health problems and related intervention strategies” (Stokols, 1996, p. 287) without exclusively focusing on one domain in promoting health behavior change. The model also supports increasing attention in the public health field to the role of the wider social context in largely

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[9] Adapted from McLeroy et al. (1988)

determining health behaviors and outcomes (Braveman and Gottlieb, 2014, Andermann and Collaboration, 2016, World Health Organization, n.d.). Additionally, constructs from other theories, e.g. behavioral, organizational, etc. can be applied at the various levels of the SEM to increase its explanatory power, resulting in a more comprehensive understanding of how specific factors may influence health and health behaviors, including the mechanisms through which they occur (Sallis et al., 2015).

As highlighted in Chapter 1, multiple personal and environmental factors affect the development, behaviors and wellbeing of adolescents. Thus, the SEM's focus on the multi-faceted factors affecting health outcomes and behaviors, make it highly applicable to the study of adolescent experiences. For example, it has been applied to explore a variety of adolescent health behaviors associated with substance abuse (El Kazdouh et al., 2018, Ssewanyana et al., 2020, Turner et al., 2020, Jacobs et al., 2020, Neumark et al., 2012); diet and physical activity (Van Hecke et al., 2016, Pawlowski et al., 2014, Ssewanyana et al., 2018a, McCormick et al., Townsend and Foster, 2013); SRH outcomes (Batista Ferrer et al., 2016, Ezenwaka et al., 2020, Rizvi et al., 2020, Markham et al., 2020, Jonas et al., 2020); effects of child maltreatment (Saupe et al., 2020, Schneiderman et al., 2015) and other problem and/or risk behaviors (Ssewanyana et al., 2019, Livazović and Bojčić, 2019, Peskin et al., 2017). For example, El Kazdouh et al. (2018) found that perceived benefits of substance use, family and peer influence, social norms and easy accessibility were risk factors for substance abuse among Moroccan adolescents.

With regards to HIV/AIDS the SEM has been used to identify risky sexual behaviors (El Kazdouh et al., 2019, Harper et al., 2014), barriers and facilitators to adherence to ART (Galea et al., 2018), retention in treatment (Enane et al., 2020) and factors affecting the experiences of ALHIV (Hosek et al., 2008, Mburu et al., 2014b). For example, Galea et al. (2018) found that poor health due to suboptimal adherence, ART misinformation and side effects, affected ART adherence among Peruvian adolescents. Among adults it has been applied in understanding HIV risk factors (Gourlay et al., 2017, Frew et al., 2016, Logie et al., 2018a), barriers and facilitators to access and utilization of HIV services (Dirisu et al., 2020, Onono et al., 2015, Tumwine et al., 2019, Iwuji et al., 2020, Dyson et al., 2018), ART adherence challenges (Sheehan et al., 2021, Becker et al., 2020, Storholm et al., 2019, Castro et al., 2015, O'Laughlin et al., 2020), mental health (Ashaba et al., 2017, Wouters et al., 2016), quality of life (Lacombe-Duncan and Chuang, 2018, Cianelli et al., 2020) and parental disclosure (Qiao et al., 2015). These studies demonstrate that multi-level factors affect the health and health behaviors of individuals across various health conditions, populations and diverse settings and that multi-faceted and multi-sectoral responses are required to improve population health outcomes.

A limitation of the SEM is its potential for “over-inclusivity” of factors which might affect it’s utility. It has been argued that over-inclusive models make it difficult for researchers and policy-makers to decide which factors to target and address, where and how best to intervene (Stokols, 1996). In addition, the SEM does not give any indication about how the factors work together or which factors have greater influence on behavior change. The SEM is useful in identifying factors or levels for interventions affecting health behaviors but lacks theoretical guidance on which factors are more important or at which level to intervene for the greatest impact on a health behavior. However, the SEM is a comprehensive and very useful framework to explore, identify and understand factors affecting the health status and health behaviors of adolescents.

2.4.1 Streamlining an approach to context: applying the SEM within this thesis

Given the model’s focus on the physical and social influences on health behavior, the SEM will be applied as a conceptual framework to explore and examine factors shaping the lived experiences of ALHIV. It will contribute to the development of a holistic and context based understanding of the multi-level factors influencing the lived experiences of ALHIV, specifically highlighting how the social environment shapes the experiences of ALHIV and their engagement with treatment. Its application will facilitate consideration of the dynamic and complex interplay of individual, interpersonal, community, institutional and policy factors that support and/or prevent ALHIV from engaging in treatment and that shape experiences across the life course of ALHIV. For example, in the previous chapter (Chapter 1) various factors across socio-ecological levels shaping the health and wellbeing of adolescents were described, including poverty, poor access to education and employment, high disease burden, social norms, lack of accessible health services (e.g. AFHS) and a political environment that is not responsive/conducive to the needs of adolescents (e.g. poor implementation and enforcement of adolescent policies, restrictive SRH policies, etc.).

The SEM informed the formation of the research questions, the presentation of results and the interpretation of findings of the systematic review (Chapter 3) and the in-depth qualitative study of the lived experiences of ALHIV in Lusaka, Zambia (Chapter 5, Chapter 6 and Chapter 7). The SEM informed the research and methods of this thesis, including topic guide development and data analysis which is described in greater detail in 0. It also contributed to the development of two adapted socio-ecological models demonstrating the diverse influences on the health experiences of ALHIV in the context of HIV and factors shaping ART adherence decisions and behaviors among adolescents (Chapter 8). The SEM provides a useful framework for understanding the experiences of ALHIV in resource limited settings and for contextualizing the findings of this thesis to inform intervention, policy and future research.

Conclusion

This chapter introduced the theoretical framework guiding this thesis examining the lived experiences of ALHIV in Zambia. It discussed three models (HBM, IMB and SEM) that have been widely used to examine health behaviors and their application in HIV/AIDS research and studies examining the experiences of PLWH. Unlike the more cognitive based HBM and IMB models, the SEM examines dynamic and interdependent factors at various socio-ecological levels that influence health behavior and outcomes therefore, I found it more appropriate for the examination of the experiences of ALHIV living in resource limited settings due to the diverse socio-economic and psychosocial challenges facing young people across the life course in these contexts. The findings of this thesis will contribute to the limited literature applying the SEM to examine the experiences of ALHIV.

Chapter 3 Self-disclosure experiences of ALHIV in Sub-Saharan Africa: systematic mixed studies review

3.1 Introduction

With increasing numbers of children living with HIV surviving into adolescence, self-disclosure of HIV status is increasingly important because of its implications for the wellbeing of ALHIV and for the control of the HIV epidemic (Obermeyer et al., 2011, Thoth et al., 2014, Gabbidon et al., 2020). Disclosure of HIV status is a significant challenge that ALHIV navigate during their life course and decisions to disclose and experiences of disclosure are influenced by various socio-ecological factors (Obermeyer et al., 2011). However, as outlined earlier in this thesis (Chapter 1) not much is known about the self-disclosure experiences of ALHIV. This chapter describes findings from a systematic mixed studies review on the self-disclosure experiences of ALHIV in SSA in order to provide a holistic perspective on what is known about their perceptions and experiences, including motivations, barriers and consequences of disclosure.

3.2 Background

Awareness of HIV status is critical for engagement in treatment services and disclosure of HIV status can significantly affect engagement in treatment and care e.g. linkage, treatment initiation and retention. However, as discussed in **Error! Reference source not found.**, many adolescents are unaware of their HIV status and ALHIV have poor treatment outcomes. Self-disclosure of HIV status is also associated with numerous benefits including, increased social support (Patel et al., 2012, Atuyambe et al., 2014, Smith et al., 2008, Dessalegn et al., 2019, Shacham et al., 2012); increased adherence (Buma et al., 2015, Dessie et al., 2019, Heestermans et al., 2016, Govindasamy et al., 2012); retention in care (Umeokonkwo et al., 2019, Arrive et al., 2012, Akilimali et al., 2017) and prevention of onward transmission of HIV (Ostermann et al., 2015, King et al., 2008, Dessalegn et al., 2019, Ssali et al., 2010). However, in order to realize these benefits in controlling the HIV epidemic adolescents must disclose their status to others. The literature has identified four types of disclosure associated with adolescents: parents/caregivers disclosing their status to the adolescent; the adolescent's own status being disclosed to them; parents/caregivers informing others of the adolescent's status; and the adolescent themselves informing others of their own HIV status (Mburu et al., 2014a).

The literature regarding parental disclosure of HIV status has reported on rates of parental disclosure, facilitators and barriers and impact of such disclosure on children and parents. Studies have found generally low rates of parental disclosure to children (Jantarapakde et al., 2019, Appiah et al., 2019, Osingada et al., 2016, Qiao et al., 2013). Facilitators of parental disclosure include: educating or protecting children from HIV (Qiao et al., 2013, Osingada et al., 2017, Rwemisisi et al., 2008, Tiendrebeogo et al., 2013, Muparamoto and Chiweshe, 2015); preparing children for potential poor health or death of parents (Qiao et al., 2013, Rwemisisi et al., 2008, Muparamoto and Chiweshe, 2015); worries child will learn of parental HIV status from someone else (Muparamoto and Chiweshe, 2015, Rwemisisi et al., 2008, Qiao et al., 2013), belief that children have a right to know/obligation to disclose (Qiao et al., 2013, Osingada et al., 2017, Muparamoto and Chiweshe, 2015); and to obtain care and support (Avornyo and Amoah, 2014, Qiao et al., 2013). Barriers to parental disclosure include: concern that children are too young and wouldn't be able to understand the implications of an HIV diagnosis (Qiao et al., 2013, Osingada et al., 2017, Avornyo and Amoah, 2014, Muparamoto and Chiweshe, 2015, Kennedy et al., 2010); not knowing how to disclose (Nam et al., 2009, Kennedy et al., 2010, Madiba, 2013, Osingada et al., 2017, Qiao et al., 2013); worried children will tell others which could lead to stigma and discrimination (Qiao et al., 2013, Osingada et al., 2016, Avornyo and Amoah, 2014, Muparamoto and Chiweshe, 2015, Madiba, 2013); worries over responding to potential questions from children about how they were infected (Appiah et al., 2019, Muparamoto and Chiweshe, 2015); and worries about negative psychological consequences of disclosure (Avornyo and Amoah, 2014, Nam et al., 2009, Qiao et al., 2013, Madiba, 2013, Osingada et al., 2016), e.g. emotional pain. Mixed impacts to parental disclosure have been reported, especially among children (Qiao et al., 2013). Positive outcomes include improved parental psychological wellbeing or relief (Qiao et al., 2013, Osingada et al., 2017, Tiendrebeogo et al., 2013); child support and concern for parental health (Tiendrebeogo et al., 2013, Osingada et al., 2017, Rwemisisi et al., 2008, Avornyo and Amoah, 2014, Qiao et al., 2014); emotional and practical support (Kennedy et al., 2010, Tiendrebeogo et al., 2013, Osingada et al., 2017) and improved or closer parent-child relationships (Kennedy et al., 2010, Qiao et al., 2013, Tenzek et al., 2013). Negative outcomes include shock and concern/anxiety over parent's wellbeing (Qiao et al., 2013, Kennedy et al., 2010, Qiao et al., 2014, Osingada et al., 2017).

Similarly, the literature concerning disclosure of a child's own HIV status has reported findings on the rates of disclosure, facilitators, barriers, and impact of such disclosure on children. Studies report generally low rates of disclosure to children (Britto et al., 2016, Vaz et al., 2011, Doat et al., 2019, Bulali et al., 2018, Abegaz et al., 2019). Facilitators of disclosure to children include: initiation of ART and improvement in adherence (Britto et al., 2016, Vreeman et al., 2013, Vaz et al., 2011, Doat et al., 2019); child's right to know their status (Britto et al., 2016, Doat et al., 2019); increasing age of child (Britto et al., 2016, Vreeman et al., 2013, Vaz et al., 2011, Doat et al., 2019) and child asking questions (Vreeman et al., 2013, Doat et al., 2019). Barriers to disclosure of child's HIV status include: concern over the child being too young and/or unable to understand implications of an HIV diagnosis (Britto et al., 2016, Vreeman et al., 2013, McHugh et al., 2018, Doat et al., 2019, Vreeman et al., 2010); fear of parental disclosure (Domek, 2010, Mandalazi et al., 2014); parental shame or guilt (Vreeman et al., 2013, Britto et al., 2016); worried child will tell others leading to potential stigma and discrimination (Domek, 2010, Britto et al., 2016, Vreeman et al., 2013, Vaz et al., 2011, Doat et al., 2019); fear of tough questions from child (Mandalazi et al., 2014, Doat et al., 2019, Finnegan et al., 2019) e.g. how they were infected; not knowing when and/or how to disclose (Domek, 2010, Britto et al., 2016, Vreeman et al., 2013, McHugh et al., 2018, Doat et al., 2019); child not asking questions about their health (Domek, 2010); negative psychological consequences of disclosure (Britto et al., 2016, Vreeman et al., 2013, Mandalazi et al., 2014, Vaz et al., 2011, Doat et al., 2019), e.g. upsetting the child and fear of child resentment (Vreeman et al., 2013). Reported impacts of disclosure include: negative emotional reactions (Vreeman et al., 2013, Britto et al., 2016, Doat et al., 2019), e.g. sadness and worry and improved adherence to ART (Britto et al., 2016, Namasopo-Oleja et al., 2015, Doat et al., 2019, Bulali et al., 2018). The WHO has also produced guidelines to help health care workers support children and caregivers with HIV status disclosure to a child living with HIV (World Health Organization, 2011). There is a paucity of literature regarding parents/caregivers informing others of the child's HIV status.

The literature on self-disclosure highlights a lack of clarity and consistency in how self-disclosure is defined and measured, making it difficult to meaningfully compare or assess the practice within and across populations (Obermeyer et al., 2011). However, despite variation studies on disclosure have generally defined self-disclosure as an individual revealing their HIV status to others (Evangeli and Wroe, 2017, Kennedy et al., 2015, Yonah et al., 2014), with certain studies exploring specific audiences of disclosure, e.g. sexual partners. For the purposes of this review self-disclosure is defined as an individual informing others of their HIV status. The decision to disclose one's HIV status is complex and adult studies have shown that many factors influence decisions to disclose and whom to disclose to. These include type and quality of relationship (Sowell et al., 2003, Derlega et al., 2004); and the consideration of potential benefits and negative consequences (Rodkjaer et al., 2011, Sowell et al., 2003). Reported facilitators of self-disclosure include ill health and/or physical changes (King et al., 2008, Ssali et al., 2010, Deribe et al., 2008, Hays et al., 1993, Kiranga); HIV prevention/awareness (Ssali et al., 2010, Chandra et al., 2003, Derlega et al., 2004, Kiranga, Dessalegn et al., 2019); relationship ties (Sowell et al., 2003, Derlega et al., 2004, Ssali et al., 2010); access to social support (Neville Miller and Rubin, 2007, Patel et al., 2012, Ssali et al., 2010, Rice et al., 2009, Dessalegn et al., 2019); access to treatment (Kiranga, Ssali et al., 2010, King et al., 2008); information and education from counseling (Dessalegn et al., 2019, Greeff et al., 2008) and knowledge of partner's status (Deribe et al., 2008, Niccolai et al., 2006). Reported barriers to self-disclosure include not wanting to upset or worry others (Medley et al., 2004, Neville Miller and Rubin, 2007, Hays et al., 1993, Ssali et al., 2010, Dessalegn et al., 2019); fear of blame (King et al., 2008, Maman et al., 2003, Greeff et al., 2008, Kiranga, Walcott et al., 2013); fear of rejection and/or abandonment (Ssali et al., 2010, Deribe et al., 2008, Paiva et al., 2011, Kiranga, Dessalegn et al., 2019); fear of violence from partners (King et al., 2008, Deribe et al., 2008, Medley et al., 2004, Dessalegn et al., 2019, Walcott et al., 2013), futility (Hays et al., 1993, Chandra et al., 2003); fears concerning confidentiality of their HIV status (Ssali et al., 2010, Neville Miller and Rubin, 2007, Greeff et al., 2008, Maman et al., 2003, Driskell et al., 2008) and discrimination and stigma (Deribe et al., 2008, Chandra et al., 2003, Greeff et al., 2008, Medley et al., 2004, Kiranga). The factors affecting self-disclosure may differ among adolescents as they have unique needs and face distinct challenges from children and adults, e.g. the changes experienced during adolescence may make navigating self-disclosure of HIV status especially challenging for adolescents who may already be struggling with issues of identity and belonging. Due to the increased burden of HIV among adolescents, poor treatment outcomes and importance of disclosure in navigating life with HIV, e.g. social relationships, it is important that adolescent experiences of self-disclosure, including motivations, barriers and facilitators are understood to enhance engagement with HIV treatment and care and improve health outcomes in this population.

The literature has also shown that supportive relationships with family and peers are critical to the psychosocial wellbeing of adolescents (Maurizi et al., 2013, Moore et al., 2018, Lucktong et al., 2018, Dekovic et al., 2002). However, to gain such support ALHIV need to disclose their HIV status. Despite this importance there is a lack of research focusing on the perceptions and experiences of self-disclosure among ALHIV (Thoth et al., 2014, Gabbidon et al., 2020), especially in resource limited settings. Therefore, this review aims to enhance our understanding of adolescent experiences with self-disclosure by focusing on the experiences of ALHIV in SSA.

Objectives

In order to explore the perceptions and experiences of self-disclosure of HIV status among ALHIV, this review is guided by the following questions:

1. What are the perceptions and experiences of ALHIV towards self-disclosure of HIV status?
2. What is the impact of self-disclosure on the wellbeing of adolescents?
3. What are the barriers and facilitators to self-disclosure?
4. What interventions exist to enable self-disclosure among ALHIV?

3.3 Methods

A Systematic Mixed Studies Review (SMSR) is a type of literature review involving the synthesis of qualitative, quantitative and mixed method studies (Pluye and Hong, 2014). This approach promotes a more comprehensive understanding of an issue, by integrating evidence from diverse studies and findings from either type can also better explain or contextualize findings from the other (Cerigo and Quesnel-Vallée, 2020, Hong and Pluye, 2019). Therefore, I chose to conduct an SMSR because I felt it was an appropriate method to generate a comprehensive understanding of the self-disclosure experiences of ALHIV in SSA. This review was conducted following the Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA) (Moher et al., 2009) and prior to commencement this review was registered on the PROSPERO database (CRD42019119704).

Eligibility criteria

I aimed to retrieve studies reporting findings on the experiences of self-disclosure among ALHIV, as well as studies reporting interventions enabling self-disclosure for this population. Any articles published before February 2019 were eligible for inclusion. An article was included if it met the following criteria: (a) it was an empirical study reporting findings related to self-disclosure of HIV status (b) participants were ALHIV aged between 10-19; (c) described interventions enabling self-disclosure among ALHIV; and (d) studies were based in Sub-Saharan Africa. Studies with samples that included a broader age range were excluded if they did not present disaggregated findings for adolescents. Studies not reporting self-disclosure related findings were also excluded.

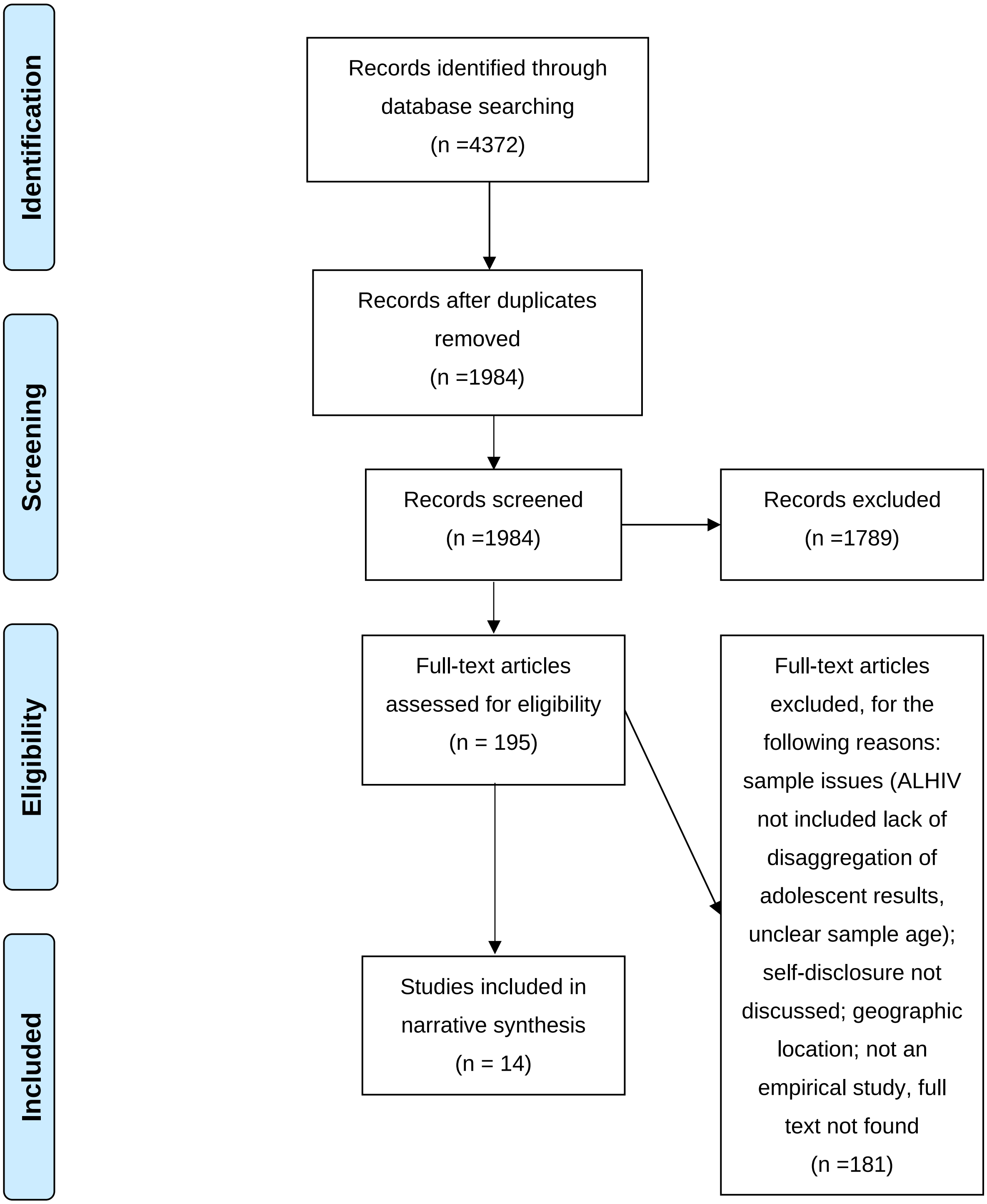
Search strategy

A selective sampling strategy was used in order to identify studies reporting findings on the review's specific phenomena of interest, population and geographical location. The literature search consisted of searching electronic databases and grey literature. Six databases were searched: CINAHL, Medline (PubMed), Embase, PsycInfo, Scopus and Web of Science. Grey literature sources included UNAIDS, UNICEF and WHO websites and their available databases, e.g. WHO's Global Health Observatory and the reference lists of included studies were also searched.

The search strategy included both text and index word searching for the following four concepts: (a) HIV or AIDS; (b) adolescents aged 10-19 years old; (c) HIV status self-disclosure; (d) Low- and middle-income countries (LMICs). LMICs were defined using the World Bank Country list and included countries classified as upper middle income, lower middle income and low-income economies (The World Bank, n.d.). Multiple variations and combinations of these concepts were used in order to conduct a comprehensive search across databases. The search terms were connected using Boolean operators “AND” and “OR”. An example of the search strategy is included in Appendix F. Endnote version X8 (Clarivate, Philadelphia, PA, USA) was used to facilitate the identification of duplicates and manage citations.

Once the articles were retrieved and duplicates removed they underwent an initial screening process. This involved screening their titles and abstracts with the aim of excluding studies irrelevant studies. Following this initial screening of titles and abstracts, studies not meeting the inclusion criteria were excluded and the full text of the remaining studies were screened against the inclusion criteria for inclusion in the review. The outcome of the search strategy is detailed in the PRISMA flow diagram below (Figure 3-1).

Figure 3-1: PRISMA flow diagram



Critical appraisal

Critical appraisal is an important step in the conduct of SMSRs and are conducted to assess the conceptual, methodological and reporting quality of included studies (Hong and Pluye, 2019). There are four main approaches applied in the critical appraisal of SMSRs (Hong and Pluye, 2019). One approach involves solely appraising the quality of the dominant qualitative or quantitative component of the mixed study review (Hong and Pluye, 2019). A second approach involves applying specific criteria for appraising mixed methods studies that includes criteria for assessing quantitative, qualitative and mixed method studies e.g. Mixed Methods Appraisal Tool (Hong and Pluye, 2019). A third approach involves applying generic criteria that can be used to assess all studies (Hong and Pluye, 2019). Lastly, specific criteria designed for assessing qualitative and quantitative components of studies, e.g. specific critical appraisal tools (Hong and Pluye, 2019). I chose the last approach because quantitative and qualitative studies have different methodological and epistemological traditions and I felt using checklists designed for the appraisal of the specific study designs would provide a better understanding and/or representation of the trustworthiness of included studies (Hong and Pluye, 2019).

The quantitative and qualitative studies were assessed using the Standard Quality Assessment Criteria for evaluating primary research due to its capacity to critically appraise a variety of studies (Kmet et al., 2004). This process involved using independent checklists for specific quantitative and qualitative study designs to rate specific aspects of the study including, design and data collection strategies. The quantitative checklist includes fourteen criteria and the qualitative checklist ten. Response options include: met criteria, partially met criteria and failed to meet criteria. Each response was scored. If a study met a criteria it received two points, if it partially met the criteria it received one point and it if failed to meet the criteria it received zero points. Criteria that were not relevant to the study were marked as not applicable. A total score for each study was calculated by summing the scores on each criteria and dividing it by the total potential score to achieve a score between 0 and 1. Studies were categorized as very good if they had scores of 0.80 and above, good if they had scores of 0.70 to 0.79 and poor if they had scores below 0.70.

The mixed methods studies were assessed using the Mixed Methods Appraisal Tool (MMAT) version 18 as it is a validated tool that includes criteria to assess mixed methods studies (Hong et al., 2018, Carragher and McGaughey, 2016). The studies were assessed according to five criteria. Responses were categorized as meeting criteria, not meeting criteria and unsure or “can’t tell” if criteria is met. Summary scores are discouraged using the tool therefore studies were assessed as very good if they satisfied all the criteria, good if they met at least three criteria and poor if they met less than three criteria. Studies were not excluded based on the results of the critical appraisal due to the risk of disregarding important insights into the self-disclosure experiences of ALHIV (Hannes, 2011), especially since the quality of reporting due to various reasons (e.g. journal manuscript length requirements) may lead to the exclusion of methodologically and conceptually sound studies (Hong and Pluye, 2019, Huwiler-Müntener et al., 2002).

Data extraction

An extraction table was used to record study findings. Data were extracted on authors; date of publication; setting; sample; study aim and design; methods and findings, e.g. outcomes of HIV status self-disclosure including, perceptions of self-disclosure, experiences of disclosure, impact of disclosure, and barriers and facilitators of self-disclosure of HIV status (Table 3-3). For studies describing interventions data were extracted on authors; year of publication; setting; sample; study aim and design; intervention components and duration; methods and findings, including feasibility and acceptability of the intervention (Table 3-4).

Data Analysis

There are a variety of methods used to synthesize qualitative and quantitative findings including meta-analysis, meta-ethnography, realist synthesis, narrative synthesis, critical interpretive synthesis, etc. (Hong et al., 2017, Heyvaert et al., 2016). However, there are two major types of synthesis designs applied in the synthesis of quantitative and qualitative evidence in the conduct of SMSRs: sequential and convergent synthesis designs (Hong et al., 2017, Stern et al., 2020, Creswell and Clark, 2017). In sequential synthesis designs the collection of data and analysis of one type of evidence informs the data collection and analysis of the other type (Hong et al., 2017, Noyes et al., 2019). For example, findings from a synthesis of quantitative evidence informs the collection and analysis of the qualitative synthesis. In convergent synthesis designs, the collection and analysis of qualitative and quantitative data occurs at the same time in a complementary manner (Hong et al., 2017, Noyes et al., 2019). I adopted a convergent synthesis design because it was better suited to address the exploratory research questions guiding this review (Fetters et al., 2013).

Three subtypes of convergent synthesis designs have been identified: parallel-results convergent synthesis, results-based convergent synthesis and data-based convergent synthesis (Hong et al., 2017). Parallel-results convergent synthesis involves the separate analysis and presentation of extracted quantitative and qualitative data using similar and/or different methods with the integration of the syntheses occurring in the discussion (Hong et al., 2017). Results-based convergent synthesis involves the separate analysis of extracted quantitative and qualitative data using similar and/or different methods and the combination of the separate syntheses together in a third synthesis (Hong et al., 2017). Lastly, data-based convergent synthesis, which is applied in this review, involves the analysis of qualitative and quantitative data using a similar method and the results of the synthesis are presented together (Hong et al., 2017). Quantitative research is concerned with producing generalizable data summarizing the experiences of a population using numbers whereas qualitative research is concerned with participant perspectives and experiences, and provides information on the context making it well suited to explore complex phenomena (Eyisi, 2016, Hammarberg et al., 2016). The triangulation of both types of evidence allows for a better understanding of what is occurring and why therefore, a data-based convergent synthesis design was chosen to enhance the complementary nature of qualitative and quantitative evidence to create a comprehensive account of the literature on the self-disclosure experiences of ALHIV.

I used textual narrative synthesis as the method to synthesize evidence because of its usefulness in describing the scope of existing research and synthesizing data using different methods (Heyvaert et al., 2016, Lucas et al., 2007). The approach involved three stages: textual narrative synthesis of the qualitative data, textual narrative synthesis of the quantitative data and integration of the findings from both the qualitative and quantitative syntheses. The textual narrative synthesis included analysis of the results and discussion sections of included studies. The synthesis process involved the organization of studies into sub-groups according to which of the review questions they addressed to facilitate comparison between and across studies (Popay et al., 2006, Lucas et al., 2007). Data relating to each of the review questions was extracted from both the qualitative and quantitative studies. For example, data relating to barriers to disclosure were extracted to address the question concerning “barriers to disclosure” and data relating to who ALHIV disclosed their HIV status to were extracted by type of relation e.g. “disclosed status to family/friend/romantic partner/teacher”, etc. to address the question about experiences of disclosure. The extracted evidence was then described, paying attention to differences within and between studies (Popay et al., 2006, Lucas et al., 2007).

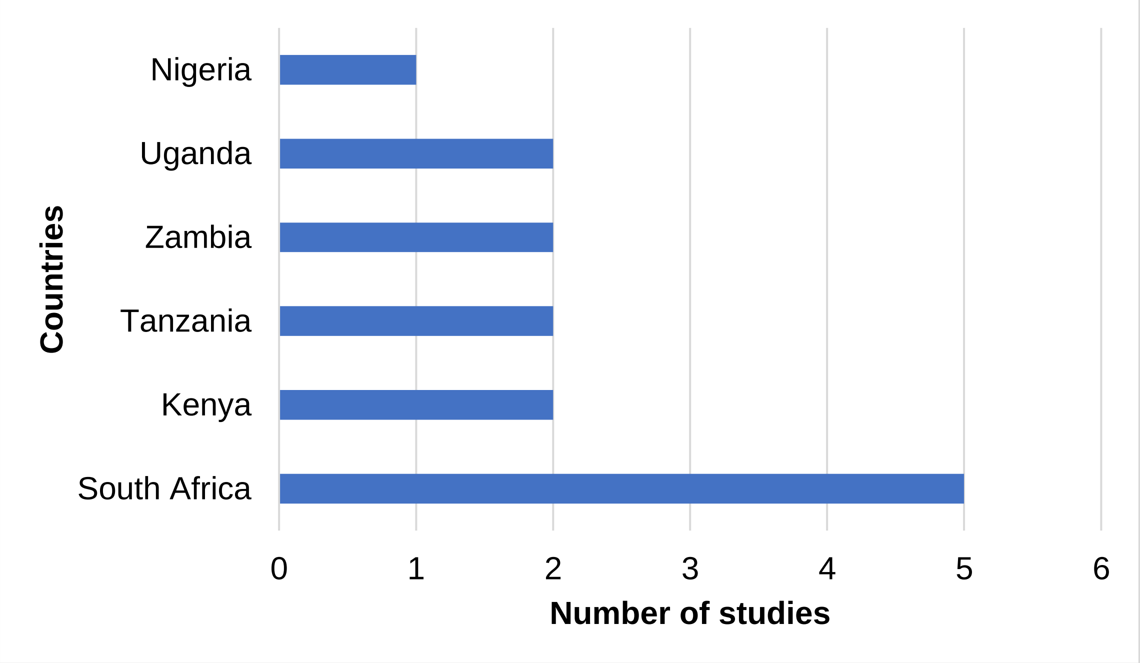
3.4 Results

A total of 4,372 articles were identified from the search. There were 1,984 articles left after the removal of duplicates. The title and abstracts of these articles were screened and 1,789 were excluded as they were not relevant to the objectives of this review. The full text of 195 articles were then reviewed for inclusion, of which 180 were excluded because they did not meet the inclusion criteria (Figure 3-1). The remaining 14 studies that met the inclusion criteria were included in the review.

Characteristics of included studies

The included studies took place in six countries in SSA: Kenya (Abubakar et al., 2016, Nöstlinger et al., 2015), Nigeria (Dulli et al., 2018), South Africa (Madiba and Mokgatle, 2016, Mavangira and Raniga, 2015, Petersen et al., 2010, Pienaar and Visser, 2012, Toska et al., 2015), Tanzania (Daniel, 2015, Midtbø et al., 2012), Zambia (Mburu et al., 2014a, McCarraher et al., 2018), and Uganda (Nöstlinger et al., 2015, Mutumba et al., 2015a) (Figure 3-2).

Figure 3-2: Study locations



Adolescent participants across the studies ranged in age from 10-19 years old. The studies predominantly examined the experiences of vertically infected adolescents (Abubakar et al., 2016, Mutumba et al., 2015a, Madiba and Mokgatle, 2016, Mavangira and Raniga, 2015), three examined the experiences of both vertically and horizontally infected adolescents (Mburu et al., 2014a, Toska et al., 2015,

McCarraher et al., 2018) and the other studies did not provide details on mode of HIV infection. The studies took place in predominantly urban settings (Mutumba et al., 2015a, Petersen et al., 2010, Pienaar and Visser, 2012, James et al., 2018, Nöstlinger et al., 2015, McCarraher et al., 2018) but also included rural (Abubakar et al., 2016), mixed urban and rural (Madiba and Mokgatle, 2016, Midtbø et al., 2012, Mburu et al., 2014a, Daniel, 2015, Toska et al., 2015) and mixed suburban and rural settings (Dulli et al., 2018). Eight studies included health care providers and/or caregivers in the sample (Petersen et al., 2010, Mavangira and Raniga, 2015, Daniel, 2015, Mburu et al., 2014a, Midtbø et al., 2012, McCarraher et al., 2018, Abubakar et al., 2016, James et al., 2018) and two discuss interventions related to self-disclosure of HIV status (Dulli et al., 2018, James et al., 2018). Ten studies employ qualitative methodology (Abubakar et al., 2016, Daniel, 2015, Madiba and Mokgatle, 2016, Mavangira and Raniga, 2015, Mburu et al., 2014a, Midtbø et al., 2012, Petersen et al., 2010, Mutumba et al., 2015a, Pienaar and Visser, 2012, James et al., 2018), one quantitative (Nöstlinger et al., 2015) and three mixed methods (McCarraher et al., 2018, Dulli et al., 2018, Toska et al., 2015) (Figure 3-3: Study methodology).

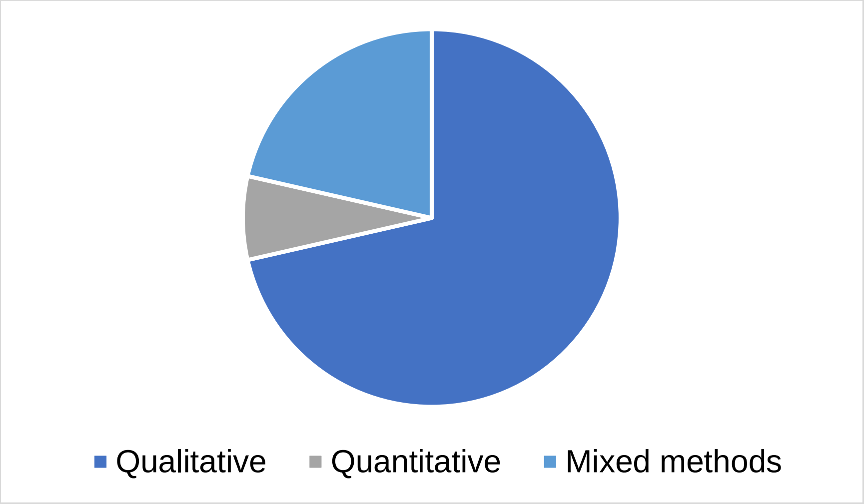
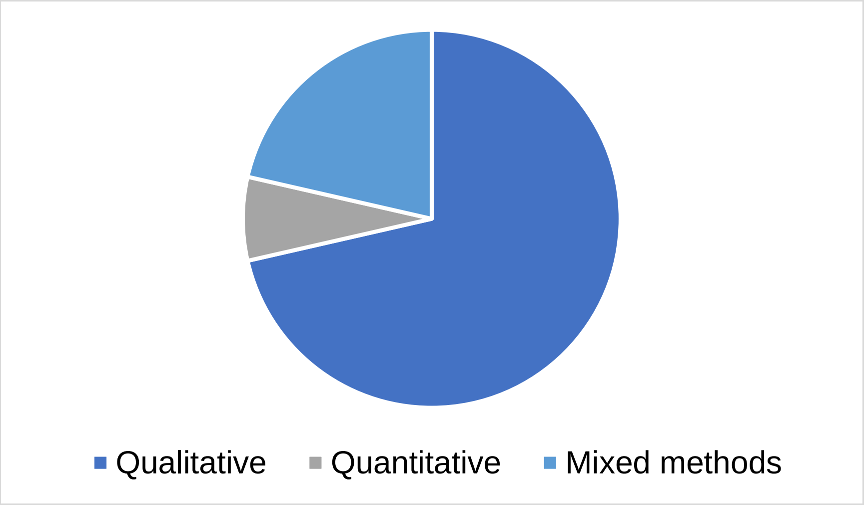


Figure 3-3: Study methodology



Critical appraisal outcomes

Overall the studies were considered to be of good quality with all the studies clearly stating the aims of the research, providing a rationale for the data collection methods and using appropriate data collection and analysis methods. Nine of the eleven studies assessed using the Standard Quality Assessment criteria were considered very good quality (Mutumba et al., 2015a, Madiba and Mokgatle, 2016, Mburu et al., 2014a, Mavangira and Raniga, 2015, Midtbø et al., 2012, Petersen et al., 2010, James et al., 2018, Pienaar and Visser, 2012, Nöstlinger et al., 2015) and two were considered to be of good quality (Abubakar et al., 2016, Daniel, 2015) (Table 3-1). Limitations of the qualitative studies related to lack of sufficient description of the sampling strategy and analytic methods (Daniel, 2015, Abubakar et al., 2016) and evidence of reflexivity (Mavangira and Raniga, 2015).

Table 3-1: Critical appraisal for quantitative and qualitative studies

Qualitative studies			
Study	**Total Sum**	**Total Possible Sum**	**Summary Score**
Abubakar et al. (2016)	14	20	0.70
Mutumba et al. (2015)	18	20	0.90
Madiba and Mokgatle (2016)	17	20	0.85
Midtbø et al. 2012	17	20	0.85
Mavangira and Raniga (2015)	18	20	0.90
Mburu et al. (2014)	17	20	0.85
Petersen et al. (2010)	18	20	0.90
Pienaar and Visser (2012)	16	20	0.80

Daniel, 2015	15	20	0.75
James et al. (2018)	16	20	0.80
Quantitative studies			
Study	**Total Sum**	**Total Possible Sum**	**Summary Score**
Nöstlinger et al. (2015)	17	20	0.85

Two of the three studies assessed using the MMAT were considered to be of very good quality (Toska et al., 2015, McCarraher et al., 2018) and one to be of good quality (Dulli et al., 2018) (Table 3-2). A limitation of one of the mixed method studies was the lack of a rationale for the study design (Dulli et al., 2018).

Table 3-2: Critical appraisal for mixed methods studies

Study	Rating
Toska et al. (2015)	Very good
McCarraher et al. (2018)	Very Good
Dulli et al. (2018)	Good

Table 3-3 below describes the results of the data extraction for non-intervention studies that includes information on study design, methods and findings relevant to the aims of this review. Information on adolescent perceptions, experiences, impact, motivation and barriers to self-disclosure are described. The table shows that disclosure to others is rare, with low rates of disclosure reported across studies. It also shows that participants experienced both positive (e.g. social and treatment support) and negative reactions (e.g. stigma) and that numerous barriers prevent adolescents from disclosing their status.

Table 3-3: Data extraction on disclosure experiences

Authors, publication year	**Setting**	**Sample**	**Study Aim**	**Study design and Methods**	**Findings**
Mutumba et al. (2015a)	•Kampala, Uganda •Large treatment center	N=38, Perinatally infected 13-19 year old's	Qualitative cross-sectional study exploring the psychosocial challenges and coping strategies among ALHIV.	•Qualitative cross-sectional study using semi-structured interviews •Phenomenological approach to data analysis using open thematic analysis	Disclosure experiences •Several adolescents reported limited disclosure at home •3/11 of those in relationships had disclosed to their partners (all girls) who reacted positively •Limited disclosure to trusted peers, teachers, partners, teachers, health workers and religious leaders in order to receive practical and emotional support. Impact •Lack of disclosure: reinforced feelings of isolation from siblings and peers;

Authors, publication year	Setting	Sample	Study Aim	Study design and Methods	Findings
					heightened emotional distress; and undermined adherence (especially non-disclosure within families). •Some received practical and emotional support (e.g. medication reminders, informational support about HIV, and emotional support with dealing with isolation or distress related to HIV) Barriers •Fear of discrimination, loss of control over information and avoidance of pity (disclosing to family members) •Fear of losing friends, further stigmatization, being gossiped about and being pitied (disclosing to friends and sexual partners) •Fear of abandonment and disclosure of status to others (disclosing to current partners) •Caregivers instructing adolescents not to disclose their status in the home due to the potential for discrimination from family members

Authors, publication year	Setting	Sample	Study Aim	Study design and Methods	Findings
Pienaar and Visser (2011)	•Pretoria, South Africa •HIV clinic	N=6, adolescents aged 13-17	Describe the experiences of ALHIV in order to understand how their experiences living with HIV influence their identities.	•Qualitative cross-sectional study using semi-structured interviews and expressive art. •Social constructionist narrative approach.	Disclosure experiences •Majority of participants had not disclosed beyond their immediate family. •One participant disclosed his status to his teachers. Impact •Participant who told his teachers about his status receives support from them, e.g. sending him home when he is ill. Barriers •Fears of rejection and stigma. •A participant's grandma told him not to disclose his status out of fear of negative reaction from others.
Petersen et al. (2010)	•Durban, South Africa •Urban hospital	N=40, 25 ALHIV aged 14-16 and 15 caregivers	Examine psychosocial challenges and protective factors among adolescents and caregivers.	•Qualitative cross-sectional study using individual interviews •Data analyzed thematically using framework analysis approach	Disclosure experiences •13 participants had not disclosed beyond their immediate care-giving family •Beyond immediate family disclosure occurred in school context (n=10) and/or one friend (n=3) Impact

Authors, publication year	**Setting**	**Sample**	**Study Aim**	**Study design and Methods**	**Findings**
					•Adolescents mostly reported greater academic support and understanding related to disclosure to teachers. Barriers •Fears of stigma and discrimination.
Mavangira and Raniga (2015)	•Gauteng, South Africa •Two child and youth care centers	N=20, 8 ALHIV aged 14-16; 2 social workers and 10 youth care workers	Explore the psychosocial experiences and coping strategies used by perinatally infected adolescents.	•Qualitative cross-sectional study using an interpretive descriptive design •Semi-structured interviews with adolescents and FGDs with social workers and youth care workers •Data analyzed thematically using Marlow's framework for thematic analysis and narrative thematic analysis	Perceptions •Disclosure should occur in secure and trusting relationships Impact •Secrecy and lack of information impacts treatment adherence Barriers •Lack of secure and trusting relationships with friends •Fears of being teased •Fears surrounding HIV among people
Daniel (2015)	•Iringa, Tanzania	N=17, 13 ALHIV aged	Explore how HIV-positive children	•Qualitative longitudinal/cross-sectional study using	Disclosure experiences

Authors, publication year	Setting	Sample	Study Aim	Study design and Methods	Findings
	•HIV treatment center	10-15 and 4 adult workers	respond to the disclosure process and the perceived need for secrecy and silence concerning living with HIV	an exploratory design •IDIs	•Several participants kept their status secret because they had been asked to do so by caregivers •One participant reported keeping his status secret of his own accord •Two participants were initially open about their status until they were stigmatized •One participant is open about his status as he does not practice any form of secrecy •Some participants report 'partial disclosure' (in-between full disclosure and total secrecy of status) to friends or relatives, where they would mention something related to their status e.g. giving another reason for visiting the treatment center Impact •Stigma •Keeping status secret deprives participants of social support and negatively affects key relationships (e.g. with family and peers) Barriers

Authors, publication year	**Setting**	**Sample**	**Study Aim**	**Study design and Methods**	**Findings**
					•Several ALHIV instructed by caregivers to keep status •Feeling ashamed •Fear and experience of stigma
Mburu et al. (2014a)	•Kalamo, Kitwe and Lusaka; Zambia •Government ART clinics and neighboring community and youth centers	N=170, (111 ALHIV aged 10-19; 21 parents and guardians; and 38 health care providers)	Explores disclosure of HIV status to adolescents, adolescents' disclosure to others and the impact of both on adolescents.	•Qualitative cross-sectional study •Semi-structured interviews and focus group discussions	Perceptions of disclosure: •Participants expressed the desire to control disclosure (including whether to disclose and to whom) Disclosure experiences • Limited disclosure to peers in school setting • 2/27 adolescents in sexual relationships disclosed their status to their partners Impact •Loss of romantic relationships •Support with adherence from family and friends Barriers •Fear of stigma •Fear of rejection and abandonment by romantic and/or sexual partners

Authors, publication year	Setting	Sample	Study Aim	Study design and Methods	Findings
Abubakar et al. (2016)	•Kilifi, Kenya •HIV clinics, the community and secondary schools	N=44, (12 vertically infected ALHIV aged 12-17; 7 HIV uninfected adolescents aged 12-17; 11 caregivers of ALHIV; 8 HSPs and community health workers and 6 teachers and education administrators)	Investigate the experiences and challenges of ALHIV	•Qualitative cross-sectional study using semi-structured key informant interviews •Data analyzed using framework analysis	Perceptions of disclosure: •HIV status seen as a secret that needs to be protected •Most of the adolescents preferred 'partial disclosure' (where only a few people who must know about their status are told) to family and peers •Non-disclosure seen as the best way to avoid negative social consequences Impact •Not disclosing within immediate environment led to some experiencing constant worry over their status being exposed and problems with medication management Barriers •Fears of rejection, isolation and stigmatization
Madiba and Mokgatle (2016)	•Mpumalanga and Gauteng provinces, South Africa •ART and primary	N=37, vertically infected ALHIV aged 12-18	•Explore the experiences of PAH and examine their perceptions and	•Qualitative cross-sectional study using an exploratory design	Perceptions of disclosure •Some participants felt that in general disclosure to other people is important •Some felt disclosure beyond family is not a good idea

Authors, publication year	**Setting**	**Sample**	**Study Aim**	**Study design and Methods**	**Findings**
	healthcare clinics		experiences of disclosure and on-ward self-disclosure to friends, sexual partners, and others.	•IDIs using semi-structured interview schedule •Data analyzed using thematic analysis.	•Most considered their HIV diagnosis a secret and that it was not important to share it with others •Nature, length and/or quality of the relationship was an important consideration for disclosure •Adolescents expressed the desire to control to whom and when to disclose their status Disclosure experiences •Most adolescents decided to keep their status a secret •8/37 disclosed their status to others: 4 disclosed to a friend or friends and 4 disclosed to a teacher •Some of the adolescents who disclosed to friends experienced stigma which led to secrecy and emotional trauma Impact •Some participants reported social support from friends (e.g. emotional support and medication reminders)

Authors, publication year	**Setting**	**Sample**	**Study Aim**	**Study design and Methods**	**Findings**
					•Emotional trauma after experiencing negative reactions to disclosure (e.g. isolated by friends) Barriers •Fear of being gossiped about •Experiences and fear of stigma •Fear of rejection and isolation •Fear of negative reactions from friends and romantic partners and being treated differently •Fear that their status will be shared with others without their consent •Caregivers instructed some participants to not disclose their status to anyone
Midtbø et al. (2012)	•Tanzania (NGO)	N=14, (12 ALHIV aged 12-14 and 2 healthcare staff members)	Explore how ALHIV find opportunities for managing their lives and coping with stigma in the context of ART and disclosure	•Qualitative cross-sectional study using a phenomenological design •Semi-structured interviews	Perceptions of disclosure •Most participants would not disclose their status beyond their family Disclosure experiences •A few participants shared their status with a few friends they found trustworthy and had positive experiences

Authors, publication year	**Setting**	**Sample**	**Study Aim**	**Study design and Methods**	**Findings**
					•Some participants shared their status with their teachers to enable social support when facing stigma at school Impact •Support and understanding from friends •Support from teachers when experiencing stigma Barriers • Told not to disclose their status by caregivers, fear of stigma, and lack of knowledge about HIV transmission among people
Nöstlinger et al. (2015)	•Kampala, Uganda and Nyanza province, Kenya •Health care facilities (clinics, youth centers providing HIV testing and community-	N=582 ALHIV aged 13-17	Examine self-disclosure to peers, perceived HIV-related stigma, self-esteem, and social support among ALHIV	•Quantitative study based on a secondary data analysis and using a cross-sectional questionnaire	Perceptions of disclosure •Majority of the sample's self-efficacy to disclose was in the normal range but a quarter of the sample had low self-efficacy to disclose Disclosure experiences •Mean number of people participants disclosed their status to was 0.7 (SD=0.9) •43.5% (n=253) of participants reported that they had told nobody except health-care providers of their status

Authors, publication year	**Setting**	**Sample**	**Study Aim**	**Study design and Methods**	**Findings**
	based health centers)				•1 in 5 reported having told their peers about their HIV status •17.9% (n=104) reported disclosure to peers, of which the majority or 72.2% (n=83) received positive reactions that they found helpful with few reporting that the reactions they received were never helpful [7.8%] •Of those who reported having a boyfriend or girlfriend, 34.3% (n=80) reported discussing their status with their partner, with the majority 66.3% (n=53) reporting positive reactions of which 81.2% (n=65) found sometimes or always helpful •Self-disclosure was significantly associated with study location; older age; being a paternal orphan; having to contribute to family income; attending the HIV clinic monthly or more often; higher self-efficacy to disclose; lower levels of negative self-image; having experienced less stigmatizing public attitudes and more perceived social support through peers. •Significant predictors of self-disclosure include being older; being a paternal orphan; having to contribute to family income; visiting the HIV clinic every 2-3

Authors, publication year	**Setting**	**Sample**	**Study Aim**	**Study design and Methods**	**Findings**
					months or more often and greater perceived social support through peers. Impact •Participants found reactions from peers generally positive and helpful Barriers •Low-self efficacy to disclose was negatively significantly associated with self-disclosure.
Toska et al. (2015)	•Eastern Cape, South Africa •Health centers	N=858, vertically and horizontally infected ALHIV aged 10-19	Mixed methods study exploring whether knowledge of self and partner HIV status and disclosure to partners is associated with safer sex.	•Quantitative questionnaires; IDIs; FGDs and direct observation at health facilities. •Multivariate logistic regressions and grounded theory approach to qualitative data analysis.	Disclosure experiences •Low rates of disclosure of HIV status to partners •35.5% of those who were sexually active and in relationships disclosed their status to their partners. Impact •Disclosing one’s status to partner was not associated with safer sex. Barriers •Fears of: losing sexual desirability; public exposure; being rejected; being abandoned and being stigmatized

Authors, publication year	**Setting**	**Sample**	**Study Aim**	**Study design and Methods**	**Findings**
McCarraher et al. (2018)	•Copperbelt province, Zambia •3 HIV clinics	•Qualitative sample: N=65, 32 ALHIV aged 15-18; 23 caregivers and 10 clinical staff •Quantitative sample : N=312 ALHIV aged 15-19	Assess the SRH needs of ALHIV and the extent to which they are being met	•Mixed methods study using IDIs and a cross-sectional survey	Disclosure experiences •Disclosure to sex partners was rare •10% of survey participants who had sex reported that their first sexual partner knew their status Barriers •Fear of gossip or rejection by partners

3.4.1 What are the perceptions and experiences of ALHIV towards self-disclosure of HIV status

Six studies discussed perceptions held by adolescent participants toward self-disclosure of HIV status (Mavangira and Raniga, 2015, Mburu et al., 2014a, Midtbø et al., 2012, Nöstlinger et al., 2015, Abubakar et al., 2016, Madiba and Mokgatle, 2016). Two of these studies highlighted the importance of disclosure (Madiba and Mokgatle, 2016, Abubakar et al., 2016). In the study by Madiba and Mokgatle (2016), some participants felt that in general disclosure to other people is important but others felt that disclosure to others, particularly disclosure outside of the immediate family was not a good idea. This sentiment was echoed by participants in the study by Abubakar et al. (2016) in which participants felt that only a few people who must know about their status are aware of it and in the study by Midtbø et al. (2012), in which most participants reported that they would not disclose their status beyond their family. In the study by Nöstlinger et al. (2015) a quarter of participants displayed low self-efficacy to disclose their HIV status.

Many participants reported or displayed negative emotions or uneasiness when it came to discussing disclosure. In the study by Madiba and Mokgatle (2016) many felt that disclosing their status to their friends would be difficult and felt anxious about it. In the study by Mavangira and Raniga (2015) participants displayed feelings of anxiety, uncertainty and anger when asked about sharing their status with family or friends.

Trust was considered to be very important for disclosure to occur. For instance in the study by Mavangira and Raniga (2015), all participants expressed that they did not want to discuss their status with their friends as they did not consider the relationships secure. In the study by Midtbø et al. (2012) and Mutumba et al. (2015a) participants reported disclosing their status to a few individuals whom they trusted. Madiba and Mokgatle (2016) found that the nature, duration and quality of the relationship were important considerations among participants when it came to disclosing their status.

Despite this, many participants felt that their HIV status was their secret and not to be shared with others (Midtbø et al., 2012, Madiba and Mokgatle, 2016, Abubakar et al., 2016). In the study by Madiba and Mokgatle (2016) participants considered their diagnosis their secret which they did not feel was necessary or important to share with others. Similarly, Abubakar et al. (2016) reported that participants saw their status as a secret that needed to be protected. In the study by Midtbø et al. (2012), many participants decided to keep their status a secret due to concerns of experiencing stigma. However, many participants expressed the desire to control disclosure of their status, including to whom and when (Madiba and Mokgatle, 2016, Mburu et al., 2014a).The literature on perceptions of disclosure among ALHIV is varied, with participants expressing mixed feelings towards disclosure across studies and most choosing to keep their status a secret or limiting disclosure to those they are closest to, e.g. immediate family.

Most of the studies described experiences of participants with onward disclosure of their HIV status, with ten discussing who participants had disclosed to, reasons why and the associated consequences (Daniel, 2015, Mburu et al., 2014a, Midtbø et al., 2012, Nöstlinger et al., 2015, McCarraher et al., 2018, Madiba and Mokgatle, 2016, Toska et al., 2015, Mutumba et al., 2015a, Pienaar and Visser, 2012, Petersen et al., 2010). The types of people who participants disclosed to varied and included romantic and/or sexual partners, friends/peers, teachers, health care providers and family members.

Five studies discussed disclosure to romantic and/or sexual partners (Toska et al., 2015, Mutumba et al., 2015a, Mburu et al., 2014a, Nöstlinger et al., 2015, McCarraher et al., 2018), with low rates of partner disclosure across studies. In the study by Toska et al. (2015) only 34.9% (45.8% of girls and 13.5% of boys) reported that their partners were aware of their status and among those that were sexually active, only 35.5% reported that their sexual partners were aware of their status. Similarly, McCarraher et al. (2018) reported that only 10% of participants who had sex reported that their first sexual partner was aware of their status (40% girls and 10.3% boys). In the study by Nöstlinger et al. (2015) 34.3% of participants who reported being in a relationship had discussed their status with their boyfriends or girlfriends (37.3% girls and 30.3% boys) and in the study by Mutumba et al. (2015a) 27% (3/11) of participants in relationships reported disclosure to their partners. In the study by Mburu et al. (2014a) only 7.4% (2/27) of participants in sexual relationships reported having disclosed their status to their sexual partners. Two studies reported positive consequences of disclosure to romantic and/or sexual partners (Mutumba et al., 2015a, Nöstlinger et al., 2015). In the studies by Mutumba et al. (2015a) and Nöstlinger et al. (2015) participants who disclosed their status to their partners received positive reactions, e.g. social support. One study described loss of relationships as a result of disclosure (Mburu et al., 2014a).

Four studies discussed disclosure to teachers within the school context (Petersen et al., 2010, Pienaar and Visser, 2012, Midtbø et al., 2012, Mutumba et al., 2015a). In the study by Mutumba et al. (2015a) participants disclosed their status to a few teachers they could trust in order to receive practical and emotional support. Similarly, in the study by Midtbø et al. (2012) participants reported sharing their status with teachers in order to receive social support when experiencing stigma at school. Disclosure to teachers provided participants with increased academic and social support, especially when experiencing difficulties at school (Petersen et al., 2010, Pienaar and Visser, 2012, Midtbø et al., 2012).

Six studies discussed disclosure to friends and/or peers and reported mixed reactions (Petersen et al., 2010, Daniel, 2015, Mburu et al., 2014a, Midtbø et al., 2012, Madiba and Mokgatle, 2016, Nöstlinger et al., 2015). In the studies by Midtbø et al. (2012) and Mutumba et al. (2015a), a few participants reported sharing their status with friends they considered trustworthy. Midtbø et al. (2012) described positive consequences of such disclosure, with participants reporting understanding and support from friends. In the study by Madiba and Mokgatle (2016), a few had disclosed their status to friends, with some receiving support and others experiencing stigma. Mburu et al. (2014a) found that among participants disclosure to peers at school was rare and limited. In the study by

Petersen et al. (2010) very few participants reported having disclosed to friends. In the study by Nöstlinger et al. (2015) 17.9% of participants reported disclosing their status to peers, which included friends, boyfriends or girlfriends and schoolmates (17.2% girls and 18.6% boys). The majority of participants in this study who disclosed to peers reported receiving positive reactions that they found helpful (72.2%) (Nöstlinger et al., 2015). In the study by Daniel (2015), two participants reported disclosing their status to friends and were stigmatized.

Two studies discussed disclosure in the health care setting (Nöstlinger et al., 2015, Mutumba et al., 2015a). In the study by Nöstlinger et al. (2015) 43.5% of participants reported not having told anyone about their status except health care providers and in the study by Mutumba et al. (2015a) participants reported disclosing to health workers for practical and emotional support.

Most of the studies focused on self-disclosure outside the family, and did not explore disclosure within families. Due to the unique position of adolescents, in-between childhood and adulthood, immediate family members or at the very least caregivers may already be aware of their status, especially if they were infected vertically, like most of the ALHIV in SSA. For instance, Mburu et al. (2014a) found that adolescents did not always decide who to inform about their status at home as household members were usually aware of the adolescents’ status. However, when families were mentioned it was usually to emphasize that those participants had not disclosed beyond their immediate families, or that they practiced limited disclosure within their families of their own volition and/or under instruction by caregivers (Daniel, 2015, Midtbø et al., 2012, Mutumba et al., 2015a). Participants in the studies by Daniel (2015), Midtbø et al. (2012) and Mutumba et al. (2015a) reported being told by caregivers to keep their status secret.

3.4.2 What is the impact of self-disclosure on the well-being of adolescents?

Positive and negative impacts of disclosure on the wellbeing of ALHIV were described, with five studies describing positive impacts of disclosure (Nöstlinger et al., 2015, Midtbø et al., 2012, Petersen et al., 2010, Pienaar and Visser, 2012, Mutumba et al., 2015a), one negative impacts (Daniel, 2015) and two both positive and negative impacts (Madiba and Mokgatle, 2016, Mburu et al., 2014a). In the studies by Madiba and Mokgatle (2016), Midtbø et al. (2012), Petersen et al. (2010) and Mutumba et al. (2015a) participants described receiving emotional support from friends, family, teachers, and health care providers, which included understanding, encouragement and support with dealing with isolation or distress related to their status and HIV-related stigma. Participants in three of the studies also reported treatment-related support, including medication reminders, being escorted to the clinic and informational support about HIV from friends, family, partners and health care providers (Madiba and Mokgatle, 2016, Mburu et al., 2014a, Mutumba et al., 2015a). One study discussed the impact of self-disclosure on safe sexual practices and found that disclosure was not associated with safer sex (Toska et al., 2015). Negative impacts of disclosure included, emotional distress or trauma, stigma and discrimination (Daniel, 2015, Madiba and Mokgatle, 2016).

Four studies discussed the impact of non-disclosure of HIV status on the wellbeing of ALHIV (Daniel, 2015, Abubakar et al., 2016, Mutumba et al., 2015a, Mavangira and Raniga, 2015). Abubakar et al. (2016) found that not disclosing within their immediate environment (e.g. family and peers) led some participants to experience constant worry over their status being exposed, which also affected their medication management. Mutumba et al. (2015a) found that lack of disclosure within the immediate environments of participants reinforced feelings of isolation from siblings and peers, heightened emotional distress and undermined adherence (especially nondisclosure within families). Similarly, Mavangira and Raniga (2015) found that secrecy and lack of information impacted treatment adherence. In addition, Daniel (2015) found that keeping their status secret deprived participants of social support and negatively affected key relationships with family and peers.

3.4.3 What are the barriers and facilitators to self-disclosure of HIV status?

Most of the studies reported barriers to self-disclosure (Abubakar et al., 2016, Mutumba et al., 2015a, Mavangira and Raniga, 2015, Nöstlinger et al., 2015, Madiba and Mokgatle, 2016, McCarraher et al., 2018, Toska et al., 2015, Petersen et al., 2010, Daniel, 2015, Mburu et al., 2014a, Midtbø et al., 2012, Pienaar and Visser, 2012). Barriers described by participants included: fears of rejection, abandonment and isolation (Abubakar et al., 2016, Pienaar and Visser, 2012, McCarraher et al., 2018, Madiba and Mokgatle, 2016, Toska et al., 2015, Mburu et al., 2014a, Mutumba et al., 2015a); fears and experience of discrimination and stigma (Toska et al., 2015, Petersen et al., 2010, Mburu et al., 2014a, Midtbø et al., 2012, Pienaar and Visser, 2012, Abubakar et al., 2016, Daniel, 2015, Mutumba et al., 2015a, Madiba and Mokgatle, 2016); fears of their status being shared with others without their consent (Madiba and Mokgatle, 2016, Mutumba et al., 2015a, Toska et al., 2015); being the subject of gossip (McCarraher et al., 2018, Madiba and Mokgatle, 2016, Mutumba et al., 2015a); being teased (Mavangira and Raniga, 2015); avoidance of pity (Mutumba et al., 2015a); anticipated negative reactions (Madiba and Mokgatle, 2016) and being instructed by caregivers not to disclose their status to others (Pienaar and Visser, 2012, Daniel, 2015, Mutumba et al., 2015a, Madiba and Mokgatle, 2016, James et al., 2018, Midtbø et al., 2012). Other barriers mentioned included feeling ashamed of their status (Daniel, 2015); lack of knowledge about HIV transmission among general public (Midtbø et al., 2012); low self-efficacy to disclose (Nöstlinger et al., 2015) and fear of losing sexual desirability (Toska et al., 2015). None of the studies explicitly discussed facilitators of self-disclosure among ALHIV. However, a few described instances where participants disclosed or would consider disclosing their status to people they considered trustworthy or with whom they had a trusting relationship (Mutumba et al., 2015a, Midtbø et al., 2012, Mavangira and Raniga, 2015).

3.4.4 What interventions exist to promote self-disclosure among ALHIV?

Two studies described comprehensive interventions aimed at addressing the psychosocial needs of ALHIV and improving health outcomes (James et al., 2018, Dulli et al., 2018) (Table 3-4). They were both found to be acceptable by participants and feasible to implement. The Integrated Access to Care and Treatment (I ACT) was adapted from an adult version and designed to facilitate early initiation of ART, promote adherence and retention in care and provide educational and psychosocial support in a group context (James et al., 2018). The groups met once a month and covered six topics: Connecting and sharing; HIV/AIDS Basics; Treatment literacy; Acceptance of Status and Disclosure; Sexual Reproductive Health and HIV transmission; Nutrition and Self-care and HIV Prevention and Risk Reduction, including mental health (James et al., 2018).

The Social Media to promote Adherence and Retention in Treatment (SMART) Connections initiative was adapted from another initiative and was designed to promote adherence and retention in HIV care through enhancing various forms of social support (Dulli et al., 2018). The study was limited to five of the fourteen sessions of the original Positive Connections initiative, and included sessions on: Understanding HIV; Disclosure and Developing Trust in relationships; Treatment and Adherence; Nutrition and Health and Sex and Relationships (Dulli et al., 2018).

Despite both interventions having sessions on disclosure, only one described changes in self-disclosure perceptions or practice (Dulli et al., 2018). In the study by Dulli et al. (2018), one participant expressed increased confidence to disclose and described being unafraid to disclose her status to her partner before marriage. Both studies described some implementation challenges. The study by James et al. (2018) described some human and material challenges including lack of materials and resources to implement session activities, lack of space and lack of well-trained staff to implement the support groups consistently. The study by Dulli et al. (2018) described human and logistical challenges including variability in active participation on the part of facilitators and participants and participant difficulty with network coverage and availability of data. Despite the challenges encountered, both interventions were found acceptable to adolescents and feasible to implement.

Table 3-4 below presents the results of the data extraction that includes information on study design, methods, and findings concerning self-disclosure interventions. Information on intervention components and delivery, outcomes and experiences of participants and the acceptability and feasibility of the interventions are described. The table shows that both interventions took place in South Africa, were administered differently and found to be feasible and acceptable.

Table 3-4: Data extraction on self-disclosure interventions

Author, publication date	Setting	Sample	Study aim	Intervention components and duration	Study design and methods	Findings
James et al. (2018)	South Africa	23 (15 ALHIV aged 15-19; 4 facility managers and 4 health care providers)	Explores the feasibility of conducting I ACT support groups for ALHIV from the perspective of health care providers and experiences of ALHIV	•Health care provider driven educational support group •Delivered in-person to groups of up to 15 ALHIV monthly	Qualitative cross-sectional study using semi-structured interviews	•Feasible initiative and acceptable to ALHIV •Some participants were instructed by family to keep their status secret
Dulli et al. (2018)	Nigeria	41 (ALHIV aged 15-19)	Develop and test the feasibility and acceptability of implementing a social media-based support group	•Online support group delivered through secret groups on Facebook •Informational messages and	Mixed methods single group pre-post study using semi-structured questionnaires and in-depth interviews	•Intervention is feasible and acceptable to ALHIV •A participant reported feeling more confident and unafraid of

			intervention to improve HIV knowledge, social support, adherence and retention among ALHIV	moderated group discussions		disclosing her status to her partner before marriage

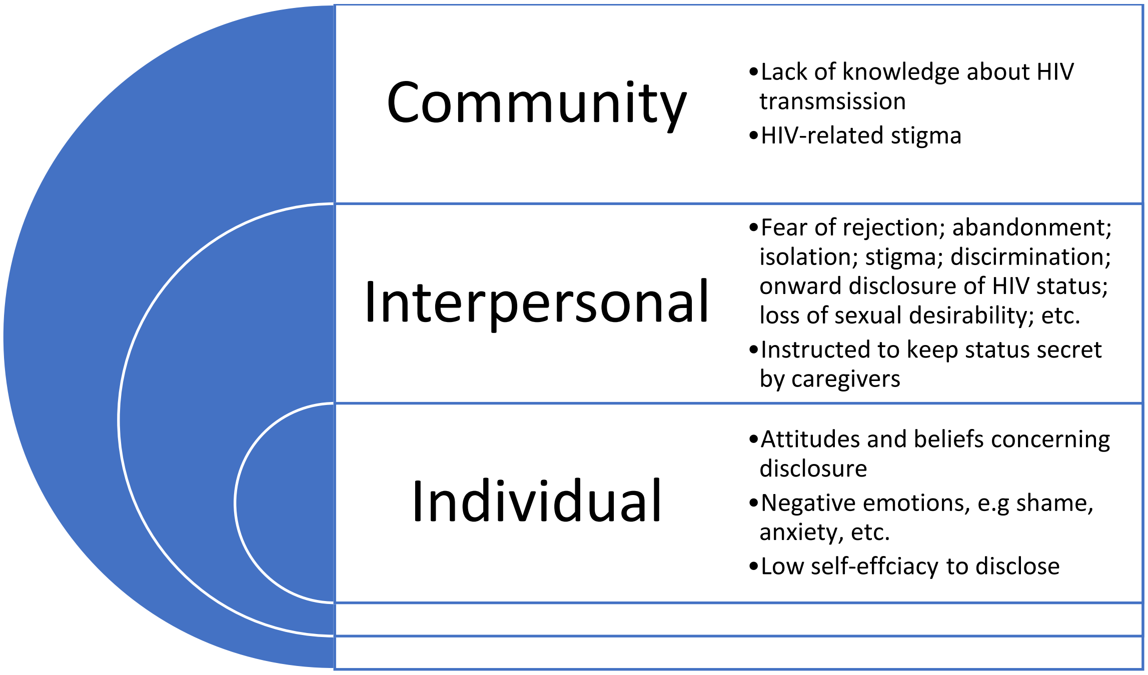
3.5 Discussion

This review aimed to identify and synthesize the existing literature on the experiences of self-disclosure among ALHIV aged 10-19 in SSA, with a focus on perceptions and experiences of disclosure, impact of disclosure on adolescent wellbeing, barriers and facilitators of disclosure and interventions that enable self-disclosure. The findings illustrate that self-disclosure of HIV status is complex and challenging and is something that ALHIV greatly struggle with, especially in contexts where HIV stigma is pervasive, as is the case in SSA (Bonnington et al., 2017).

It is evident from the included studies that onward disclosure of HIV status is influenced by many psychosocial and contextual factors. This review identified a wide range of barriers across different socio-ecological levels that prevent ALHIV from sharing their status with others (Figure 3-4) Such barriers need to be addressed in order to promote disclosure among ALHIV as disclosure has significant implications for treatment outcomes and wellbeing, including engagement with care and social support (Dessie et al., 2019, Akilimali et al., 2017, Heestermans et al., 2016).

No barriers to self-disclosure were identified at the institutional or policy levels. This lack of evidence of the impact of such structural factors in the adolescent literature has implications for the kinds of interventions being developed for this population. For example, interventions may focus more on addressing individual and inter-personal level barriers such as self-efficacy to disclose and may not focus on barriers existing at the institutional and policy level. These could include policies restricting SRH education and/or the quality of such education in schools may contribute to poor HIV knowledge among adolescents which may in turn contribute to fears over HIV status disclosure. It is important that more research into potential factors affecting disclosure at the societal level are investigated due to their wide reaching consequences on the wellbeing of ALHIV.

Figure 3-4: Barriers to self-disclosure of HIV status identified in this review



The low rates of self-disclosure to romantic and sexual partners reported in some of the studies (Toska et al., 2015, McCarraher et al., 2018, Nöstlinger et al., 2015, Mutumba et al., 2015a, Mburu et al., 2014a) is troubling as disclosure is critical for the prevention of onward transmission of HIV, as it may facilitate the practice of safe sexual behaviors (King et al., 2008). Also, as described earlier in this thesis (Chapter 1**Error! Reference source not found.**), adolescence is a time when individuals are developing their sexual identity and many become sexually active (Kar et al., 2015). A lot is known about parent-adolescent sex communication, including barriers (Pariera, 2016, Malacane and Beckmeyer, 2016, Nundwe, 2012, Kamangu et al., 2017, Elegbe, 2018, Trinh et al., 2009) however, little is known about the barriers faced by adolescents to sex communication with sexual and romantic partners. A study based in the United States found sexual communication about sexual health topics including birth control, HIV/AIDS and condoms infrequent among adolescent dating partners (Widman et al., 2014). This suggests that the barriers to sex communication faced by adolescents may be compounded by the stigma surrounding HIV, which makes disclosure of HIV status to romantic and sexual partners increasingly challenging. More research needs to be done on the factors associated with disclosure of HIV status to sexual and romantic partners among ALHIV, in order to improve disclosure rates.

This review also highlights the difficulties of managing disclosure among ALHIV due to their unique position in a transitionary phase between childhood and adulthood. For example, ALHIV expressed the desire to control disclosure of their status (Mburu et al., 2014a, Madiba and Mokgatle, 2016) but sometimes it is out of their control, e.g. caregivers disclosing their status to extended family without their consent or caregivers telling them not to share their status with anyone. Caregiver apprehension about HIV disclosure negatively affects disclosure among ALHIV (Hogwood et al., 2013, Michaud et al., 2009). These results also highlight the problem with how adolescence is approached conceptually in the literature as the experiences of individuals aged 10-19 are lumped together despite adolescence compromising of three distinct phases of development (Chapter 1). These various phases introduce capacities in which various and unique experiences, needs and challenges are experienced by adolescents (Salmela-Aro, 2011, Suris et al., 2004, McNeely and Blanchard, 2010) which could be taken into consideration when examining the self-disclosure experiences of ALHIV as they may vary as a result of the level of psychological and socio-emotional development. In this analysis, I was not able to do so due to the lack of age-disaggregated data on the experiences of ALHIV in the included studies.

Only a few of the studies briefly discussed motivations for disclosure (Pienaar and Visser, 2012, Midtbø et al., 2012). For example, in the studies by Midtbø et al. (2012) and Mutumba et al. (2015a) participants reported disclosing their status to teachers and friends they considered trustworthy in order to gain support and understanding. More research examining the motivations for disclosure among

ALHIV is needed in order to better understand disclosure behaviors and create interventions to support and promote disclosure among this population.

There is a need for consensus on the definition of self-disclosure, in order to enhance our understanding of the self-disclosure process and its various forms across studies. Most of the studies did not provide a definition of self-disclosure, making it hard to assess the way it was defined/applied across studies, e.g. whether the various authors were referring to the same thing. Three studies explicitly stated that their focus was on self-disclosure to specific audiences (McCarraher et al., 2018, Nöstlinger et al., 2015, Toska et al., 2015). Toska et al. (2015) and McCarraher et al. (2018) focused on self-disclosure to romantic and/or sexual partners, whereas Nöstlinger et al. (2015) focused on disclosure to peers, which included friends, boy/girlfriend and schoolmates. In addition, only three studies mentioned specific types of disclosure. Nöstlinger et al. (2015) examined social self-disclosure to peers and in describing types of disclosure, Abubakar et al. (2016) and Daniel (2015) discussed partial disclosure but applied the term differently. Daniel (2015) used it to describe a middle ground between full disclosure of HIV status and complete secrecy, whereas Abubakar et al. (2016) used it to describe disclosure to a select few individuals. This illustrates how disclosure related terminology is not uniformly applied in the literature. More effort needs to be done on the part of researchers to increase uniformity in the application of disclosure terminology and studies examining self-disclosure need to be transparent about how disclosure is assessed to increase the usefulness of findings.

This review suggests a potential emerging typology of self-disclosure risk perception from the experiences of ALHIV, which suggests that the various risks associated with self-disclosure may vary depending on relationship type. As a result, the risks and potential outcomes of disclosure, including psychosocial impacts may differ and require special consideration depending on the recipient of disclosure. Four types of self-disclosure recipient relationships have been identified from the review: family, peers, romantic and/or sexual partners and teachers (Table 3-5). These relationships have different characteristics, dynamics and impacts on the wellbeing of adolescents. Family relationships, especially parent-child significantly affect the wellbeing of adolescents (Paradis et al., 2011, Shahhosseini et al., 2012, Moore et al., 2018). Caregivers are responsible for taking care of and nurturing adolescents (Langton and Berger, 2011) and significantly affect their decision making and behaviors (Aufseeser et al., 2006).There are potential differences based on type of family relation and immediate and/or extended family members. Peers play an increasingly important role in the lives of adolescents (Salmela-Aro, 2011). They significantly affect the interests, attitudes, values and behavior of adolescents (McNeely and Blanchard, 2010), with peer acceptance having positive effects on adolescent social and mental development (Sentse et al., 2010, Rohrbeck, 2003). Peer relations often referred to friends and/or schoolmates in the included studies.

Sexual and romantic relationships play a key role in adolescent development (Manning et al., 2014) and as adolescents develop their sexual identity, they become increasingly interested in and involved in romantic and/or sexual relationships (McNeely and Blanchard, 2010, Salerno et al., 2015). Lastly, adolescents spend a lot of time in school and their teachers have important influences on their wellbeing (Cohall et al., 2007, Fredriksen and Rhodes, 2004, Sarkova et al., 2014), with the teacher-student relationship having specific implications for adolescent development (Fredriksen and Rhodes, 2004, Roshandel and Hudley, 2018). For example, perceived teacher support has been found to significantly affect the formation of adolescent self-concepts (Roshandel and Hudley, 2018). Reported risks of self-disclosure varied by type of disclosure recipient. For example, risks with disclosure to family included fears of losing control of information, stigma and discrimination (Mutumba et al., 2015a, Abubakar et al., 2016); risks involved with disclosure to romantic and/or sexual partners related to fears of negative reactions, onward disclosure of HIV status, being gossiped about, being pitied, isolation, rejection and abandonment (Mutumba et al., 2015a, Mburu et al., 2014a, Madiba and Mokgatle, 2016, Toska et al., 2015, McCarraher et al., 2018); risks involved in peer relationships included fears of negative reactions, being teased, being gossiped about, being pitied, fears over losing relationships, isolation, onward disclosure of HIV status, stigma and discrimination (Midtbø et al., 2012, Madiba and Mokgatle, 2016, Abubakar et al., 2016, Mburu et al., 2014a, Daniel, 2015, Mavangira and Raniga, 2015, Petersen et al., 2010, Pienaar and Visser, 2012, Mutumba et al., 2015a); and risk of disclosure to teachers included stigma and discrimination (Abubakar et al., 2016). Although there is some overlap in perceived risk, it may be assumed that these risks may manifest in different ways depending on the type of relationship between the adolescent discloser and recipient (Table 3-5)

Table 3-5: Risks associated with disclosure by relationship type

Family	**Romantic and/or sexual partners**	**Peer relationships (e.g. friends)**	**Teachers**
• Discrimination • Loss of information control • Being pitied	• Fear of negative reactions • Being pitied • Rejection • Gossiped about • Onward disclosure of HIV status • Isolation • Abandonment	• Fear of negative reactions • Being pitied • Being teased • Loss of friendship • Isolation • Rejection • Gossiped about • Onward disclosure without permission	• Stigma • Rejection • Isolation

There is a need for context-specific and developmentally appropriate interventions addressing the self-disclosure needs of adolescents in SSA. This review only identified two interventions that included disclosure components (James et al., 2018, Dulli et al., 2018). The interventions were comprehensive and addressed a variety of topics relevant to ALHIV, including treatment adherence, HIV knowledge and sexual and reproductive health. They were also found to be feasible and acceptable to participants. However, none of the interventions had the specific aim of enabling self-disclosure among participants. Despite both of them including components on self-disclosure of HIV status, only one described changes in the perception of self-disclosure (Dulli et al., 2018), and it was limited to one participant. The intervention studies were focused on assessing the acceptability and feasibility of the interventions therefore, limited findings on self-disclosure may also be a result of the lack of studies examining the effectiveness of interventions targeting self-disclosure among adolescents (Thoth et al., 2014, Gabbidon et al., 2020). One of the interventions was adapted from an existing adult program which is problematic because adolescents have unique needs compared to adults and children and it is important that self-disclosure interventions reflect this.

According to the Disclosure Process Model (DPM) individuals with more positive views of disclosure are more likely to benefit from it than those who view disclosure more negatively (Chaudoir et al., 2011). Therefore, interventions enabling self-disclosure among ALHIV should focus on promoting positive perceptions of disclosure to increase the potential benefits of disclosure. As the review findings detailed negative consequences of disclosure, it is important that interventions prepare ALHIV with adequate coping skills to deal with potential negative reactions upon disclosure of their status.

None of the included interventions focused exclusively on vertically or horizontally infected adolescents. Disclosure interventions targeting ALHIV may want to consider the different needs of horizontally and vertically infected ALHIV and tailor interventions accordingly. The study by Dulli et al. (2018) demonstrated the potential of using social media and other forms of technology to support ALHIV with disclosure. As both interventions described human and material challenges, it is important that interventions designed for low-resource settings consider resource constraints in their design.

Limitations

This review is limited as it only included empirical studies written in English and due to the geographic focus. Additionally, very few of the included studies focused exclusively on self-disclosure experiences of ALHIV therefore, some of the included studies provided very little to this review. Therefore, more research is needed, specifically exploring the perceptions, experiences and motivations for disclosure in this population. Despite these limitations, this review provides a synthesis of what is known about the experiences of self-disclosure among ALHIV in SSA and highlights the need for more research in this area.

Conclusion

This review illustrates the complexities of onward disclosure of HIV status among ALHIV in SSA and the many psychosocial factors affecting disclosure. The findings of this review demonstrate gaps in the literature concerning motivation and facilitators of self-disclosure and interventions to support disclosure of HIV status among ALHIV. A better understanding of the perspectives and experiences of ALHIV can inform the development of interventions to better support this population, especially since disclosure of HIV status has implications for controlling the HIV/AIDS epidemic and improving adolescent engagement with HIV care and treatment. To address the identified gaps in the literature the experiences of self-disclosure among ALHIV with a focus on the motivations and facilitators of disclosure are explored in the qualitative phase of this thesis (See Chapter 5, Chapter 6 and Chapter 7). Disclosure of HIV status is among the significant challenges faced by ALHIV across the life course and is contextualized among the other experiences and challenges faced by this population in this thesis.

Chapter 4 Understanding relationships between context and experience: methodological considerations

4.1 Introduction

As described throughout this thesis, an in-depth understanding of the perceptions, experiences and challenges encountered by ALHIV in their everyday lives will enable improved care provision and intervention development. This chapter describes the methodology and research design for the qualitative dimensions of this thesis exploring the lived experiences of ALHIV, especially their treatment experiences along the HIV care continuum from two perspectives: adolescents and health service providers (HSPs). ALHIV were included to provide a better and more meaningful understanding of their experiences navigating life living with HIV and the challenges encountered from their own perspective. HSPs were included because of their familiarity with ALHIV as providers of HIV-related services and resources that have various consequences on the experiences of ALHIV along the care continuum. I will begin by describing the epistemological assumptions that influenced the research in this thesis and how they align with the theoretical framework discussed in Chapter 2. I will then describe the overall research design, followed by a description of the data collection and data analysis process. The data were collected using semi-structured interviews and analyzed using thematic network analysis (Attride-Stirling, 2001). I will conclude the chapter with a reflexive discussion of my experience during the research process.

4.2 Epistemological assumptions

Epistemology refers to the creation of knowledge and is concerned with how human beings come to know what they know about the world (Lewis-Beck et al., 2003). The epistemological assumptions adopted during a research process influences study design and affects judgments concerning the validity of the knowledge produced (Lewis-Beck et al., 2003). Different research traditions are interested in asking different research questions, e.g. the qualitative tradition is interested in perspectives, experiences and meaning making and the quantitative tradition is interested in quantification and measurement, e.g. measuring effects on pre-specified outcomes. I took a qualitative approach to examine the lived experiences of adolescents along the HIV care continuum as I felt qualitative methodology was the best approach to conduct an in-depth examination of the beliefs, perceptions, attitudes and experiences of ALHIV and HSPs (DeJonckheere and Vaughn, 2019).

The experiences of ALHIV are situated within and affected by the contexts in which they inhabit (Schutz, 1972). As described earlier in this thesis (Chapter 1 and Chapter 2), an individual's socio-ecological environment significantly impacts their experiences across the life course (Tomlinson et al., 2021). I draw on Schütz (1972) social phenomenology approach to examining lived experiences to frame my research into the lived experiences of ALHIV within the context of wider society. The social phenomenology epistemological assumption that knowledge is embodied in the lived experiences of individuals within the context of their everyday lives or "lifeworld" (Schutz, 1972) influenced the research design concerning the lived experiences of ALHIV from their perspective. Phenomenology is concerned with understanding the human experience of phenomena and is not concerned with explaining phenomena (Finlay, 2011). As such, researchers focus on developing holistic understandings of phenomena as they are experienced in the everyday lives of individuals. Social phenomenology is concerned with understanding the actions and experiences of individuals within the social world (de Jesus et al., 2013). In his phenomenology of the social world, Schütz emphasizes understanding the subjective experiences and meanings individuals attach to their actions within their 'life-world', a world of everyday life and immediate experiences (Costelloe, 1996, Harrington, 2000, Trujillo, 2018). Lived experiences occur in the context of an individual's everyday reality (Deep, 2020). This focus on understanding the experiences of individuals within the context of their lifeworld aligns with the aims of my thesis to explore the lived experiences of ALHIV and identify psychosocial factors shaping their experiences, particularly with HIV treatment and care. In relation to my study, the lifeworld of ALHIV refers to the overarching context in which ALHIV experience their everyday lives as they navigate living with HIV. This encompasses their experiences within the social world and across socio-ecological levels. This pre-occupation with attending to the subjective experiences of individuals within their lifeworld complements the life course approach, which highlights the influence of various social factors both proximal and distal that shape the health and wellbeing of individuals across time (Hutchison, 2005).

Schütz (1972) described concepts of the lifeworld that influence the actions and experiences of individuals including biographical situation, stock of knowledge, existential reasoning and intersubjectivity which may be helpful in understanding the experiences of ALHIV. The concept of biographical situation refers to the influence of an individual’s accumulated life experiences on their perceptions and behavior. Past experiences include both directly experienced events and indirectly experienced events (e.g. experiences of others including family and peers, etc.) (Santos, 2015). This concept highlights the importance of considering the socio-historical experiences of individuals in understanding their lived experiences, including their motivations to engage in certain actions or behaviors. The biographical situation of an individual contributes to their stock of knowledge, which refers to learned knowledge including from others, e.g. parents or peers through conversation, education, and practical experience (de Jesus et al., 2013, Schutz, 1972). An individual’s stock of knowledge works as an individual’s frame of reference, which they pull on in order to attribute meaning or make sense of their experiences in the social world (Schutz, 1972). An individual’s biographical situation and stock of knowledge affects their existential motives or reasoning for engaging in certain actions or behaviors. Schutz (1972) describes two types of motives for understanding individual actions: “in-order-to motives” and “because motives” (Schutz, 1972). In-order-to motives refer to the desired outcomes or goals anticipated from engaging in an action and because motives refer to individual experiences and accumulated knowledge, e.g. social norms (de Jesus et al., 2013, Schutz, 1972). Individuals are also influenced by their interactions with others, which is a fundamental aspect of the lifeworld (Costelloe, 1996, Kim, 1999, Schutz, 1972).This concept referred to as “intersubjectivity” refers to the world of everyday life that is shared with others, the social world in which individuals act, interact and make sense of their experiences (Schutz, 1972). It includes social interactions, knowledge, social norms, and cultural and historical elements, which significantly affect the lived experiences of individuals (Schutz, 1962, Fossey et al., 2002, de Jesus et al., 2013).

The concepts of biographical situation, stock of knowledge, existential reasoning and intersubjectivity focus attention on both the personal and external influences on the behaviors and wellbeing of ALHIV and may be useful in reflecting on their lived experiences. These lifeworld concepts further demonstrate important overlaps with the life course approach as both emphasize the influence of socio-historical experiences, knowledge and beliefs and interpersonal relations on the lived experiences of individuals. The lifeworld concepts allow me to build upon the descriptive context-based nature of the SEM and examine how knowledge of the lifeworld shapes health decision-making and behaviors of ALHIV across the life course.

Studies applying Schütz’ social phenomenology as a framework have been used to understand the experiences of socially vulnerable mothers (Munoz et al., 2013); homeless women (Biscotto et al., 2016); adults living with cystic fibrosis (Cordeiro et al., 2018); nurses providing care in primary health systems (Vera et al., 2018); unsuccessful attempts to quit smoking (Jesus et al., 2016); maintenance of tobacco abstinence (Zampier et al., 2017); drug use among women (Soccol et al., 2018) and crack cocaine use among adolescents (Mota et al., 2018). Mota et al. (2018) found that socio-environmental factors from the family (e.g. parental drug use), community (e.g. high availability of drugs) and school (e.g. peer pressure) contexts influenced cocaine use among adolescents in Brazil. Evidence from these studies demonstrates the applicability of Schütz' social phenomenological approach to understanding the experiences of ALHIV, which to the best of my knowledge has not been applied to explore the experiences of this population, enabling opportunities for a novel contribution to how we understand health related decision making among young people living with HIV.

4.3 Research design

The research into understanding the lived experiences of ALHIV was conducted using qualitative methods. The aims of this thesis and the epistemological assumptions guiding the research justify the use of qualitative methods for data collection as qualitative research is concerned with the "meanings people attach to their experiences of the social world and how they make sense of that world" (Pope and Mays, 2006, p. 4). Qualitative methodology allows for the in-depth exploration of the subjective experiences of ALHIV, including their beliefs, attitudes and experiences in the social context (Power, 1998, Rich and Ginsburg, 1999). Qualitative methods also complement the theoretical framework guiding this thesis (SEM), as it facilitates the identification and contextualization of socio-ecological factors affecting the experiences of ALHIV at the individual, interpersonal, community, institutional and policy levels from the perspective of both ALHIV and HSPs. Similarly, the focus on subjective experiences in the social phenomenology approach, highlights the importance of understanding the role of the social context on the health experiences of ALHIV, which is crucial to improving health outcomes among this population (Rich and Ginsburg, 1999). There were two components of data collection, the first focusing on the experiences of ALHIV and the second focusing on the perspectives and experiences of HSPs working with ALHIV.

Data collection took place in Lusaka, Zambia (See

Figure 1-1). Detailed description of specific sites will follow (see 4.4.1). Lusaka is the capital and largest city in Zambia and is located in Lusaka province, which has the second highest provincial prevalence of HIV in Zambia at 15.1% (Zambia Statistics Agency et al., 2019). Lusaka was chosen as a result of its high HIV prevalence rate and high concentration of HSPs from both clinical and community settings in which to recruit both ALHIV and HSPs.

Ethical approval was received from University College London Research Ethics Committee [Project ID: 13329/001] and ERES Converge Institutional Review Board [Ref No. 2018-Oct-024] (See Appendix A). Approval was also received from the Ministry of Health, including at the provincial and district levels in line with Zambian national research requirements.

4.4 Data collection

I used semi-structured in-depth interviews to collect information from adolescents and HSPs as the objectives of my research were to explore participant perceptions and experiences. I chose semi-structured interviews over other potential methods because they allow researchers the opportunity to flexibly explore the perceptions, feelings and experiences of interviewees (Jamshed, 2014) and give interviewees the opportunity to describe their experiences in the context of their lifeworld and the meanings they attribute to them. DeJonckheere and Vaughn (2019), state that “the overall purpose of using semi-structured interviews for data collection is to gather information from key informants who have personal experiences, attitudes, perceptions and beliefs related to the topic of interest” (p. 2). Semi-structured interviews are also effective for the exploration of personal and/or sensitive issues because it is easier for the researcher to develop a rapport with the participant and may help reduce participant concerns of confidentially that are common among more group-based approaches such as focus group discussions (DeJonckheere and Vaughn, 2019).

While focus group discussions are another useful method for gathering information on the perceptions and experiences of a group of individuals with the ability to help researchers identify a variety of perceptions and feelings about certain phenomena (Rabiee, 2004), they are not conducive to understanding the detailed personal experiences of individuals (Ritchie et al., 2013). Therefore, I felt it was not an appropriate method for my studies because I desire to emphasize the lived experiences of ALHIV and semi-structured interviews allowed for a more fine grained understanding of the social context at work in their lives. This is crucial to addressing the gaps in the literature on the lived experiences, specifically the psychosocial factors affecting the experiences of ALHIV in resource limited settings in SSA.

Also, due to the stigma surrounding HIV and the personal and sensitive nature of the topics discussed, some adolescent participants may not have felt comfortable sharing their personal experiences in a group context (Boyce and Neale, 2006, Powell and Single, 1996) and may have had concerns with confidentiality (Kitzinger, 1995). The collective nature of the group may also lead to participants engaging in censoring and performing behaviors, in which they adjust their disclosures and behavior to conform to the information or experiences shared by other group members (Carey and Smith, 1994, Kitzinger, 1995). Thus, semi-structured interviews was the most appropriate method of data collection because it allowed me to delve deeply into the individual biographies, perceptions and experiences of participants; collect detailed and descriptive data relevant to the aims of this study and allowed for the potential exploration of new insights that I had not previously considered. The method also aligns with the life course approach which is concerned with identifying and understanding the effects of factors across an individual's life course (Hutchison, 2011). All interviews were audio-recorded using a digital audio recorder. Data for this study were collected from four clinics providing HIV treatment services to ALHIV and eight community-based NGOs between December 2018 and April 2019. Clinics were selected because they are heavily involved in the provision of curative and preventive services to ALHIV in Zambia, which supported the potential to recruit a large sample of ALHIV and HSPs.

4.4.1 Study setting

The clinics were identified through a combination of discussions with knowledgeable individuals working in the field of HIV/AIDS in Zambia and reviewing a list of health care facilities in Lusaka province. ALHIV were recruited from four clinics (Clinics A, B, C and D) however the final analysis only included data for ALHIV from three of the four healthcare facilities (Clinic A, B and C), which will be described below. Three participants were also recruited from an NGO providing services to adolescent girls and young women but received their HIV treatment from Clinic B, therefore their narratives reflect their treatment experiences at this clinic (Table 4-1). Descriptions of the healthcare facility characteristics and the contexts in which adolescent participants in this study accessed treatment and care services are described below. Table 4-1 demonstrates that some clinics offered adolescent specific clinic days and weekend clinic hours and offered a variety of programming to support ALHIV.

Table 4-1: Healthcare context

	Clinic A	**Clinic B**	**Clinic C**	**Clinic D**
Location	Urban	Peri-urban	Urban (residential)	Urban
Size*	Large	Medium	Small	Medium
Population served	Children, adolescents and young adults (young adults are transitioned to adult clinic at 24 years old).	Children, adolescents and adults (adolescents transitioned to adult care at 20 years old)	Children and adolescents (adolescents are transitioned to an adult facility at 20 years old)	Children, adolescents and adults (adolescents are transitioned to adult care at 20 years old)

Adolescent specific clinic days	Monday, Wednesday and Friday	Thursday	No	Friday
Weekend clinics	No	Yes	No	Yes
Support offered to adolescents	-Peer support groups -Peer educators that lead support groups and offer one-to-one support -Workshops covering various topics related to living with HIV -Nutrition support family planning	-Peer support groups -Peer navigators that assist adolescents with navigating care at the clinic -Family planning	-Workshops covering various topics related to living with HIV -Support groups for young children, adolescents and an intensive program for adolescents who are not adhering to treatment -Nutrition support	-Youth friendly corner with books and activities. -Peer support groups (including a newly formed one for pregnant ALHIV) -Family planning
Number of adolescent participants recruited at each clinic	31	8	9	5**
Number of HSP participants recruited at each clinic	5	1	4	1

*Data on patient numbers unavailable

**Adapted member checking exercise to verify identified themes

Clinic A is a large urban clinic that provides outpatient care to a sizeable adolescent patient population. It is based in a large referral hospital in a very urban part of Lusaka. During fieldwork I observed that the clinic is very busy as it caters to a large number of children and adolescents. However, due to its organization it did not seem as crowded and congested as the other three clinics. It has a very orderly system involving multiple steps that service users follow which helps to facilitate smooth clinic appointments. The clinic population is mixed with low and middle-class service users accessing services. This clinic offers adolescent specific clinic days three days a week, on Mondays, Wednesdays and Fridays. Each of the days target a specific group of adolescents (e.g. young, middle and older adolescents), however adolescents are welcome to come on either day regardless.

Clinic B is located in a peri-urban high-density low-income area characterized by poverty with many youth not in school, poor infrastructure, including poor sanitation, and high unemployment. The clinic is medium sized and based on my observations during fieldwork, it seems much too small for the size of the population it serves. It is based in the ART department of a hospital and provides outpatient care to children, adolescents and adults. Service users are mostly of low income status. The clinic itself has poor infrastructure and is very congested, with service users waiting hours to be seen. There is no seating indoors therefore service users have to wait outside and queue without any cover. However, a covered waiting area was in the process of being constructed at the time of the interviews. The clinic has adolescent specific clinic days once a week (Thursday) and offers weekend clinic hours on Saturday and Sunday.

Clinic C is a small clinic located in an urban residential middle-income area and run by an NGO in partnership with a local government clinic. During fieldwork I observed that it gets congested due to its small size as it is located in the back of a residential plot with the main building housing the office of the NGO however, it had a covered waiting area for patients with some benches. Clinic services cater specifically to children, adolescents and adult women. Service users accessing the clinic are typically lower income.

Clinic D is a clinic located in an urban low-income area and serves middle and lower income populations. From my observations during fieldwork I noticed that the clinic could get quite congested due to its medium size, there does not seem to be enough space to cater to the patients seen. It also lacks a designated waiting area so clients queue alongside the ART building. The clinic offers adolescent specific clinic days on Fridays along with weekend clinics on Saturdays. A few adolescents (n=5) were recruited to participate in a member check focus group towards the end of data collection to verify themes identified from the semi-structured interviews (Birt et al., 2016) and no individual data was used in this thesis.

HSPs were recruited from the clinics and eight NGOs. The community-based NGOs were located in high and medium density, low and middle income and urban and residential areas. The NGOs provided services and programs to ALHIV. They engaged in diverse activities, including HIV-related preventive and curative services, welfare support services, programming and various HIV-related community engagement activities (see Table 7-1 for details). The NGOs were identified through online searches and discussions with individuals involved in HIV/AIDS work in Zambia and snowball sampling from recruited participants.

4.4.2 Participant sampling and recruitment

Adolescent participants

Adolescent participants between the ages of 15-20 were recruited as they attended appointments or accessed services from three clinics and one community-based NGO providing clinical health and social support services to adolescent girls. Convenience sampling with some inclusion and exclusion criteria was used to identify and recruit participants. Participant inclusion criteria included: being HIV+, aware of their status, aged 15-19 and able to understand and communicate in Bemba, Nyanja or English.

Clinics were visited during the week on adolescent specific clinic days depending on the clinic and on weekend clinic days if offered. Peer educators assisted with participant recruitment at two clinic locations (Clinic A and B) where they facilitated peer groups during adolescent clinic days. They approached potential participants while they waited for their appointments in the waiting area or during/after peer support activities that were ongoing during the day of their appointment. Due to their relatability and familiarity with the adolescents attending the clinic, I felt the peer educators would be more approachable and adolescents might feel more comfortable initially discussing the research study with them. If interested in participating they were referred to me to further discuss the study. However, to ensure that they did not miss their appointments or suffer any other consequences, they were interviewed in two ways; either after their appointment had ended, or while they were waiting. For the latter group, peer educators would take note of their number and come and call them when it was their turn to be seen. I would pause the interview and we would resume it after their appointment.

Clinic C did not offer adolescent clinic days therefore I visited the clinic for a couple days a week over a two week period. I was assisted by clinic staff who would refer participants meeting the inclusion criteria that had completed their appointments to me. For recruitment that occurred during weekend clinic hours, I was assisted by peer mentors or navigators that were present to assist youth. They would approach waiting adolescents or ones who had completed their appointments and refer them to me. As described above, three adolescent girls were recruited from an NGO providing services to adolescent girls and young women but received treatment at Clinic B. Prior arrangements for my visit to the organization were organized with the administrative staff. Participants at this site were approached by program staff as they were accessing services during the week and referred to me if interested in participating in the study. Participants were interviewed in empty rooms, e.g. conference room, activity room, etc. However, there was one site where it was not possible to secure a private room due to lack of space at the facility therefore, interviews were conducted in a quiet corner area sectioned off from a large room (the HIV status of participants was known to the staff).I conducted all the interviews on my own, with the exception of nine conducted in both English and Nyanja with the assistance of three interpreters (more details below). As adolescent participants were referred to me by peer mentors, clinic and NGO staff, I did not collect information on refusal rates therefore I may have oversampled individuals who were more expressive (see 8.3). Interviews generally lasted between 30 to 45 minutes.

Health service provider participants

HSPs were defined as individuals involved in the provision of HIV-related curative and preventive services, including social welfare support, to ALHIV in both the clinical and community setting, e.g. clinics and NGOs. HSPs which comprised of clinic staff and NGO staff were recruited from four clinics and eight NGOs providing HIV-related clinical care, support and welfare services to ALHIV using a mixture of convenience, purposive and snowball sampling (Given, 2008). In the clinical setting, HSPs were identified with the assistance of clinic administrators, e.g. sister in charge. I approached these potential participants for recruitment at the clinic during the week on adolescent specific clinic days, which varied depending on the clinic and weekend clinics. In some instances I was also assisted by the sister in-charge in identifying potential participants to approach.

I identified HSPs in the community setting (NGOs) through online searches and discussions with individuals involved in HIV/AIDS work in Zambia which generated a list of potential participant organizations to contact for recruitment. I reached out to organizations via email or telephone and organization leads or administrative staff introduced or referred me to staff e.g. program managers, who I then contacted for recruitment and scheduled interviews which took place during the weekdays. Participant inclusion criteria included: currently providing health services, including curative and preventive services to ALHIV and being able to understand and communicate in either Bemba, Nyanja or English. Participants also suggested potential organizations and/or individuals who I could approach.

Participants were provided with information sheets and asked to sign consent forms. I recorded nonresponse from two NGOs I reached out to and one organization did not follow-up with me after my initial communication. Interviews with HSPs generally lasted between 30 to 50 minutes.

Sample size

During recruitment, I was primarily interested in having rich and representative data. A total of 51 adolescents (See Table 5-1) aged 16-20 and 19 HSPs (Table 7-1) took part in this study. The 20 year old's included in the study (n=4) had recently turned 20 (2-3 months before the interview) and were therefore able to accurately describe their adolescent experiences. The final adolescent sample consisted of 51 individuals aged 16-20 with the majority girls (n=30). The increased number of girls in my sample may be explained by the increased risk of HIV infection among young girls and women in SSA, the use of non-purposive sampling, and the fact that I was assisted with the recruitment of adolescents and did not directly approach adolescent participants. There is a smaller sample of participants experiencing middle adolescence (n=16) aged 15-17 compared to late adolescence (n=35), ages 18-20.

I was aiming for a large adolescent sample in order to collect rich data that reflected the various experiences of ALHIV. Therefore I was committed to continuing data collection until saturation was reached, the point when no new ideas/concepts were found (Busetto et al., 2020, Moser and Korstjens, 2018) and there seemed to be a lot of consensus in the information shared by participants, especially in terms of the psychosocial factors shaping their experiences. I kept saturation of concepts and themes in mind as data collection progressed. While themes had started to repeat after 35 interviews had been collected, I continued with data collection due to the potential for identifying divergent experiences and ensuring a balance across multiple recruitment sites. I was aiming for a representative group of HSPs from both the clinical and community setting and saturation was reached after 16 interviews with 18 participants (two interviews included two respondents) where I identified shared themes. I would have liked to conduct a further three or so to further confirm this however, limited time, including delays in organizations getting back to me to organize interviews and not hearing back from organizations was a challenge.

Semi-structured interviews

I developed semi-structured interview topic guides with open-ended questions based on a review of the literature, including areas of interest and gaps and also based on the topics of interest. As described in Chapter 2, the SEM is being applied as a framework to understand the psychosocial factors affecting the lived experiences of ALHIV, especially engagement across the HIV care continuum and understanding the various factors contributing to poor health outcomes. The formulation of questions on the topic guides was influenced by the five constructs of the SEM. For example, exploring the intrapersonal level of the model included asking questions and probing about perceptions and attitudes, personal experiences, including discovery of HIV status, difficulties with adherence and coping. In relation to the interpersonal level this included posing questions and probing concerning social support and relations, including with family, peers and community members. In relation to the institutional level this included posing questions about barriers and facilitators to treatment related to the clinic, including experiences related to access and receiving and/or the availability and provision of services to adolescents. Regarding the community level, this included asking questions about barriers and facilitators to treatment within the community, experiences of HIV-related stigma and coping. Finally, regarding the policy level this included asking questions about barriers and facilitators to accessing and/or providing SRH services to adolescents.

I used follow-up questions and probes to further explore concepts and ideas as they were shared by the interviewees. Adolescent interview topic guides explored their perceptions and experiences navigating living with HIV, their treatment and care experiences, difficulties faced and coping strategies (see Appendix D for topic guide). HSP topic guides explored their perceptions on the experiences and challenges faced by ALHIV and their experiences and challenges working with this population (see Appendix E for topic guide). I conducted nine adolescent interviews with the assistance of three interpreters. Interpreters were individuals who worked at the clinic or NGOs, and were very familiar with the experiences of ALHIV. One was a male peer educator and the other two were females who assisted with administration and support at a clinic and an NGO. Because of their knowledge and familiarity with working with ALHIV, participants felt comfortable sharing their experiences with them. Simultaneous interpretation during the interview allowed for the further exploration of concepts arising from the interview. During the course of data collection no new themes were added or removed from the guide, however new prompts were used to elicit more relevant and descriptive information.

I enhanced my reflexivity during data collection through keeping a journal for recording personal observations, feelings and thoughts. I wrote it in after almost every interview using bullet points. This journal informed my analysis as it helped support my memory and reflect on my experiences in the field.

4.5 Data analysis

A few transcripts were transcribed simultaneously during the data collection process however (n=10), the majority of interviews were transcribed post completion of data collection (n=60). The transcription of audio-recordings was facilitated using Express Scribe Transcription Software (NCH Software, Colorado, USA) to manage and control audio playback while I typed up the transcripts using Microsoft Word (Microsoft, Washington, USA). Nine of the adolescent interviews involved Nyanja, e.g. eight included a mix of Nyanja and English questions and responses as participants often lapsed into English and one included English responses entirely but with questions posed in Nyanja, which allowed me the opportunity to check the flow of the interview. I also had debriefings with the interpreters after each interview to review and discuss any potential issues or concerns. I checked the accuracy of the Nyanja translations with a native Nyanja speaker. The translation validation process involved checking specific excerpts of speech for six of the nine interviews using audio recordings and transcripts to examine overlap and verify the accuracy and meaning of speech. If necessary the translator suggested alternative translations. Overall the original translations were judged to be of very good quality with two instances of alternative word choice suggestions in the posing of questions. However, the suggestions did not significantly affect participant responses or the interpretation of findings. Participant name and organizations were pseudonymized during transcription, including any personally identifiable information such as birth date, place of residence, school, etc. to ensure confidentiality.

Thematic network analysis as described by Attride-Stirling (2001) was used to analyze the interview transcripts and contributed to the findings presented in Chapter 5 and Chapter 7. It was selected because of its systematic method of identifying and analyzing emerging themes and its ability to demonstrate the links between the data and overall themes using web-like structures. I hand coded the first 16 adolescent interviews because I found that it helped with the familiarization process as I became more acquainted with the data. Beyond this, I generally enjoy the tangible nature of working with paper and physically marking up codes and writing notes, as it supports the identification of patterns in the data (Braun and Clarke, 2021). However, due to the amount of interview transcripts I used NVivo software to code the remainder because of its ability to facilitate the organization of large data and coding processes.

Social ecological model

The SEM also influenced data analysis and the interpretation of findings. The SEM facilitated the identification of factors at the individual, interpersonal, community, institutional and policy levels and the consideration of interactions between diverse factors at various levels and their impact on the lived experiences of ALHIV. Identified factors were mapped onto corresponding levels of the SEM to facilitate this process and contextualize the various multi-level factors shaping the experiences of ALHIV. It also influenced the development of two conceptual models presented in Chapter 8.

4.5.1 Thematic Network Analysis

Thematic network analysis involves six steps: coding of material, identification of themes, construction of thematic networks, description and exploration of the networks, summarizing the networks and interpreting patterns. The first step focuses on the coding of the text to break it down into “manageable and meaningful text segments” using a coding framework (Attride-Stirling, 2001, p. 390). Coding frameworks were developed based on the research questions and prominent issues identified from the transcripts themselves (Attride-Stirling, 2001) and were applied to the remaining transcripts and modified as necessary.

The second step involves the identification of basic themes, which are basic descriptive patterns identified from the text. They are “simple premises characteristic of the data” and need to be interpreted “within the context of other basic themes” to be meaningful (Attride-Stirling, 2001, p. 389), as they do not reveal much about the data as a whole on their own. These themes were identified inductively and findings were contextualized using existing literature on the experiences of adolescents and adults living with HIV and the application of the socio-ecological framework (see Chapter 2). The data analysis process involved multiple close readings of the text and several iterations of coding. A mixture of hand and electronic coding using NVivo 12 software was used for the identification of basic themes.

The third step involves construction of the thematic networks. This involves arranging the basic themes into organizing themes and analyzing basic and organizing themes to develop global themes. Organizing themes are middle-order themes which result from the process of grouping together similar basic themes. Organizing themes are more abstract and summarize the “principal assumptions” of basic themes (Attride-Stirling, 2001, p. 389). Global themes are illustrative of the overall patterns in the data and are deduced from analysis of the basic and organizing themes. These themes are “both a summary of the main themes and a revealing interpretation of the texts” as a whole (Attride-Stirling, 2001, p. 389).

Once all three types of themes are identified they are arranged into thematic networks which demonstrate how the final claims/interpretations made of the data as a whole are grounded in the lowest level of the text, supporting the overall interpretation. The construction of networks was done by hand to facilitate the visualization of underlying patterns between the basic and organizing themes and to facilitate the identification of the overarching global themes. The resulting networks were then organized into tables enabling the clear presentation of patterns arising from the lowest-levels of the data. An example table from the analysis in Chapter 5 is provided below (Table 4-2).

Table 4-2: Sample network

Global theme	*Organizing themes*	*Basic themes*
Rupture of past, present and future selves	Emotional consequences of disclosure	• Shock/Surprise • Anger at parents • Doubts over future • Suicidal ideation • Relief
	Psychological consequences of disclosure	• Disbelief • Confusion • Feeling different from family/peers • Self-stigma

Step four involves the description and exploration of the thematic networks. This step involved describing the themes and their relationships to each other within the context of the global themes and noting underlying patterns (Attride-Stirling, 2001). It involved revisiting the interview transcripts and ensuring that the networks were representative of the data. Step five involves summarizing the main themes and underlying patterns. During this step the relationships underlying the thematic networks were made clear through a summary of the basic and organizing themes which provided evidence to support the overarching global themes. The final step involves interpreting the patterns that have been deduced from the thematic networks and interpreting these findings in light of the research questions and other relevant theoretical considerations. It involved contextualizing the findings within existing literature and addressing the research questions guiding the analyses.

The results using this method are presented in Chapter 5 and Chapter 7. Chapter 5 will present findings regarding the experiences of ALHIV with the HIV care continuum. It describes various psychosocial challenges experienced by ALHIV, including adjusting post-disclosure of HIV status, engaging with treatment and adherence. Chapter 7 presents the findings from the HSP analysis, which focuses on their experiences working with ALHIV. The findings from this analysis will be used to triangulate data from the adolescent findings. The interpretation of the findings focused on the identification of congruent and diverging perspectives on the experiences of ALHIV between HSPs and ALHIV and the challenges experienced by HSPs with working and providing services to this population.

4.5.2 Life course approach

I apply a life course lens to analyze the findings from the adolescent study and enhance understandings of how factors across an adolescent's life course shape their health and wellbeing (Tomlinson et al., 2021), including their engagement in care. As discussed earlier in this thesis (Chapter 1) such an approach has not been widely used to examine the lived experiences of PLWH, especially adolescents (Wallach and Brotman, 2018, Rosenfeld et al., 2016, Moore et al., 2019). The life course approach also complements the SEM as life course factors can be contextualized across socio-ecological levels. The application of the life course approach was made post-data collection. Themes were developed from the basic themes derived from the analysis presented in Chapter 5 and coupled with a review of transcripts to ensure the themes were representative of participant experiences. This approach enabled me to identify and group together various codes to reveal patterns in the data including the identification of similarities and differences relevant to the aims of the analysis. The findings from this applied life course approach examining the experiences of ALHIV are presented in Chapter 6.

4.6 Reflexivity

In this section I describe how my position as a researcher informed the research in this thesis and draw on examples from my fieldwork experience.

My position

Being Zambian and having visited Zambia a couple of times over my life and having lived in Malawi, I was quite familiar with some of the psychosocial challenges faced by individuals living in low resource settings in SSA. This was helpful in planning the research process, sampling, recruitment strategies and topic guide development. However, my background and position brought its own challenges. During fieldwork I perceived myself to be an “insider-outsider” because of my Zambian background and my Bemba name. My background and ability to identify nuances in culture and language facilitated my access to participants and spaces, allowing me a certain level of acceptance that is not often experienced by researchers considered to be “outsiders” (Yakushko et al., 2011). I also felt that my background helped me develop a rapport with participants who often seemed pleasantly surprised or slightly more at ease during recruitment when they discovered that I was Zambian despite my foreign sounding accent.

However, I was simultaneously perceived as an outsider because I do not speak any local languages and I had come from abroad. I remember occasions during fieldwork that I would introduce myself or be introduced to someone, including key stakeholders or informants and they would tease or laugh because I identified as Zambian but did not speak any local languages. I was told that I was not a "real" Zambian but a foreigner. These reactions from my fellow countryfolk were difficult, especially as a result of my background as a third-culture kid who has struggled with issues of identity and belonging but after a while I got used to it and accepted that people might have these reactions to me. When I started to expect such reactions which helped me become more adept at handling them. I was at the same time ridiculed and envied as a result of my educational background and current pursuit of a PhD, especially from an established western institution. Sometimes these feelings arose from interactions with key informants and/or adolescent participants, many of whom had not completed secondary education. I have always felt very fortunate and grateful for the opportunities I've had in this life but this research experience forced me to reflect on my various forms of privilege (Minkler et al., 2002, Yakushko et al., 2011).

My "insider-outsider" status may have influenced responses to my questions and the temporary nature of my presence may not have helped. The collection of sensitive information and recording of conversations may or may not have been a concern for some participants. However, HSPs seemed very interested in my research and my studies, often asking about both and seemed keen to participate in my study. English is one of many official languages spoken in Zambia and is taught in primary and secondary schools. Therefore communication with individuals during fieldwork including participants was not a significant challenge. However my inability to speak any of the common local languages spoken in Lusaka, meant I had to rely on interpreters for a few of the interviews with adolescents who were not comfortable conducting them in English. In the following section I describe my concerns and experiences working with interpreters.

Working with interpreters

I was assisted by three interpreters for seven of the adolescent interviews. A few participants felt that they could complete interviews in English but due to their reduced confidence using interpreters was especially helpful, as it allowed them to better express themselves and provide richer data. I had some initial concerns over using interpreters, including fears they may not pose or deliver the questions as intended; that they may misconstrue what I was saying and that the interpreters themselves may not have a good understanding of the purpose of the research and the type of information needed.

However, I mitigated these concerns by going through a process of familiarizing the interpreters with the research study, selecting experienced and knowledgeable individuals to serve as interpreters and using a simultaneous interpretation approach. Through the process of familiarizing the interpreters with the study, I discussed the aims of the research, the topic guide and explained the kind of data I was looking for. I made sure to answer any questions they had and discussed ethical issues, e.g. confidentiality of the data (Murray and Wynne, 2001).

I also made sure to discuss the role they played in the research process and this was made clear to the research participants at the start of the interviews as well. Murray and Wynne (2001) emphasize the importance of role identification in order to manage the interview process and ensure the interpreter does not breech their boundaries, e.g. take on a more active role. As I took a simultaneous interpretation approach during the interview process, it was important that the interpreters took direction from me. Interpreters also asked for permission when they wanted to ask follow-up questions, which allowed me to stay engaged in the process and also collect additional helpful information.

After each interview the interpreter and I discussed how it went and clarified any issues or misunderstandings. Due to their familiarity with the social and cultural context, they were able to provide clarity on some of the experiences described by participants by sharing their own experiences. I purposely selected individuals that had a lot of experience working closely with ALHIV and were familiar with the experiences and challenges faced by this population. I selected them at the clinic sites (n=1) or NGO (n=2) where they were based. One of them (male) had extensive experience assisting researchers on studies involving adolescents and young people living with HIV and the other two (female) had a lot of experience providing support services, including counselling, and assisting with programs for ALHIV. Having interpreters with a lot of experience working with ALHIV and familiar with the social context was very helpful, as they were able to provide advice and help contextualize certain ideas or issues discussed by participants (Plumridge et al., 2012).

I also felt more comfortable as I decided to have them simultaneously interpret what I was saying, therefore I was able to actively participate in the data collection process, check the progress and handle any potential issues or arising confusion. The interviewees also often spoke in a mix of English and Nyanja, so I was often able to understand what was being said and check to see if it aligned with the flow of the conversation, e.g. what was said earlier. This was reassuring and made me feel confident about the quality of the data being collected.

However, I encountered some challenges using interpreters during the research process. For example, using interpreters made it more difficult to establish a rapport with participants compared to my one-on-one interviews as information was constantly moving in three ways. Secondly, the issue of selective translation is possible as interpreters may have only translated some of what was said by participants, judging for themselves what was potentially important or necessary. These challenges may have implications for the outcomes of the study, including the quality of the interviews and the data collected (Murray and Wynne, 2001).

4.7 Discussion

The epistemological orientation of the research design described in this chapter is congruent with the exploratory aims of this thesis, the theoretical framework guiding it and the qualitative approach to data collection and analysis. In this chapter I outlined the epistemological assumptions that informed the qualitative data collection and analyses into the lived experiences of ALHIV. My interest in understanding the perceptions and experiences of ALHIV and HSPs is demonstrated in the application of appropriate methods to address the thesis aims and research questions guiding the analyses exploring adolescent experiences across the continuum of care and navigating everyday life.

Schütz' (1972) social phenomenology approach that knowledge is embodied in the lived experiences of individuals within their lifeworld is illustrated in the focus on the personal experiences of individuals and their interactions within the wider social context, the intersubjective social world in which they act and are acted upon by external forces. The emphasis on the social world is similarly demonstrated in the data collection tools and analysis procedures. The concepts of the lifeworld (biographical situation, stock of knowledge, existential reasoning and intersubjectivity) will also be reflected upon in the interpretation of findings on the experiences of ALHIV.

This epistemological approach complements and facilitates the exploration of the lived experiences of ALHIV, highlighting the importance of understanding the meanings individuals attach to their actions and lived experiences and the influence of the socio-environmental context on their behavior and to the best of my knowledge, no study has been influenced by and/or applied concepts from Schütz' (1972) social phenomenological approach in exploring the lived experiences of ALHIV. This approach may offer greater insight into the social factors and contexts affecting health decision-making and behaviors of ALHIV.

Together with the socio-ecological framework guiding this thesis, the epistemological assumptions support a holistic approach to contextualizing the real world experiences of ALHIV through the identification of diverse factors at the various socio-ecological levels affecting their lived experiences. The findings from the qualitative phase of this study are presented in the following three chapters. Chapter five presents the findings on the experiences of ALHIV with the HIV care continuum, focusing on their experiences with engagement in treatment and care; Chapter six presents the findings on the experiences of ALHIV across the life course and Chapter seven presents the findings from the HSP analysis on their experiences working with ALHIV in a resource limited setting.

Chapter 5 *“Sometimes I would just get the medicine throw it away and lie that I’ve taken the medicine”:* Experiences of ALHIV along the HIV care continuum

5.1 Introduction

HIV/AIDS remains a significant challenge to the health and wellbeing of adolescents, especially in Sub-Saharan Africa where the burden is highest (United Nations Children's Fund, 2020). Despite improvements in care provision and access to ART significant challenges remain. ALHIV are disproportionately affected by the HIV epidemic and compared with younger children and adults are at increased risk for poor treatment outcomes including high rates of loss to follow up and mortality (Slogrove and Sohn, 2018, Kranzer et al., 2017). HIV incidence rates are also increasing in this population, adding to the growing number of children surviving into adolescence (United Nations Children's Fund, 2020). As a result, engagement in HIV care is crucial to controlling the HIV/AIDS epidemic and improving treatment outcomes among ALWH. The continuum of care depicts the steps involved in the treatment of HIV, and includes HIV testing, linkage to care, retention in care, adherence to ART and viral suppression. However, studies in SSA have shown that ALHIV have poor engagement and treatment outcomes along the HIV care continuum (See Chapter 1) including poor rates of HIV testing, poor adherence, high rates of loss to follow up and AIDS-related deaths (Nachega et al., 2009, Auld et al., 2014). Some of the factors contributing to poor engagement and loss to follow up in this population include poor knowledge of HIV/AIDS and/or treatment of HIV, low perception of risk, side effects of ARVs, health facility characteristics including lack of AFHS, HIV-related stigma, etc. (Williams et al., 2017, Mutumba et al., 2015a, Luseno et al., 2017) which contribute to poor treatment and psychosocial outcomes (Nachega et al., 2009, Dow et al., 2016, Kim et al., 2015). ALHIV are especially vulnerable to poor outcomes as a result of the significant developmental changes and challenges they experience during adolescence which may negatively affect treatment engagement (Vreeman et al., 2017, Machado et al., 2010, Sawyer et al., 2007).

As a result of the poor treatment outcomes among ALHIV, especially in resource limited settings, understanding the experiences of ALHIV along the HIV care continuum and the barriers they face with retention in care is crucial to improving their health and wellbeing. This chapter explores the perceptions and experiences of a sample of ALHIV in Zambia with various points of the HIV care continuum including HIV diagnosis, retention in care and adherence to treatment. The findings of this chapter will contribute to the limited literature on the experiences of ALHIV in Zambia where a significant number of PLWH are lost to follow up (Sanjobo et al., 2008, Musheke et al., 2012, Grant et al., 2008) and can inform practice and the development of interventions to improve treatment engagement among ALHIV in resource limited settings.

5.2 Results

Table 5-1 depicts characteristics of participants. Many participants had lost one or both parents and reported living with family including older siblings but mostly extended family members, including aunts and uncles. A few revealed that their deceased parents had also been living with HIV. Many participants were of middle and low socioeconomic status, with some describing challenges accessing education and health services due to financial constraints. For example, most participants had completed primary education, which is free in Zambia and some completed secondary education however, many were unable to complete secondary school because of their inability to pay tuition fees.

Many participants got into care through testing positive after acute and/or bouts of serious illness that for some led to hospitalization and were tested for HIV as part of the care they received at the hospital. However, many learned of their status by being told by caregivers with some having been receiving HIV treatment unknowingly for a couple of years. Those who reported being on medication unknowingly described being given various reasons e.g. vitamins, some other less stigmatized ailment including issues with their heart, cancer, etc. when they would inquire about the reason for taking medication. These participants shared that their caregivers wanted to wait until they were older to disclose their status to them. Very few (n=3) described finding out their status through HIV testing campaigns based within their school or the community. One participant reported going to the clinic and undergoing HIV testing of his own accord as he wanted to know his status. The average age of disclosure of HIV status in this sample is 12 years with participants typically made aware of their HIV status during early to mid-adolescence. This is in line with WHO guidelines which recommends disclosure to children aged 12 and below (World Health Organization, 2011). However, two participants found out their status in late adolescence. The majority of participants were perinatally infected with HIV however, two are unsure of how they were exposed. All participants were accessing HIV care services and on ART at the time of the interview, with very few describing experiences of disengagement for a period of time. Most of the participants were on first or second-line ART, with very few having reported being on third-line therapy regimen (n=2).

Table 5-1: Participant characteristics

	N
Age (years)	
16	9
17	7
18	9
19	23
20	3
Gender	
Girls	30
Boys	21
Living situation/caregivers	
Living with parent(s)	43
Living with wider family (including siblings, grandparents, aunts, uncles)	8
Education	
Attending school	26
Completed school	17
Attending university	2
Age disclosed to (years)	
Range	6-19
Average	12
Exposure route	
Perinatally infected	49
Unsure	2
Currently receiving ART	

Yes	51
No	0

The analysis identified four global themes related to the experiences of participants along the HIV care continuum including HIV diagnosis, linkage to care, retention in care and adherence to ART, highlighting issues of particular relevance to adolescents. These themes describe their experiences after learning of their HIV status; coping with their HIV status; challenges with accessing HIV care services and adhering to treatment and management of HIV-related stigma. These experiences have implications for engagement with the HIV care continuum.

5.2.1 Rupture of past, present and future selves

Discovery of HIV status is a turning point in the lives of PLWH and this theme explores the experiences of participants after they learned of their HIV status. In discussions of their experiences learning of their HIV status participants highlighted various emotional and psychological consequences of disclosure. Post-disclosure of their HIV status participants describe experiencing a sudden shift in their identity, including a change in their perception of self and expectations of life, which has implications for identity formation during adolescence. This theme will be presented according to two organizing themes: emotional consequences of disclosure and psychological consequences of disclosure

Table 5-2: Rupture of past, present and future selves

Global theme	*Organizing themes*	*Basic themes*
Rupture of past, present and future selves	Emotional consequences of disclosure	• Shock/Surprise • Anger at parents • Doubts over future • Suicidal ideation • Relief
	Psychological consequences of disclosure	• Disbelief • Confusion • Feeling different from family/peers • Self-stigma

Emotional consequences of disclosure- "*I just thought my world has ended, my game is over*"

Participants described similar experiences upon discovering their HIV status. Initial reactions were of shock and/or surprise, anger, hopelessness and suicidal ideation. Participants described feeling shocked or surprised at discovering their status. The shock of learning one's HIV status is linked to its "unexpectedness", as it was something that they never imagined would happen to them and it disrupted the way in which they perceived themselves. Tengo and Chai illustrate this experience in the following quotes:

> *Yeah so when I found out I was HIV positive I was frankly, shocked, ahh surprised… it was really shocking for me, knowing the disadvantages of the disease without even knowing maybe the benefits which can come with it, which may help me to live a positive life (Tengo, M/16)*

> *She [mom] had a talk with me to say, “Chai you are a virgin not so”, “yes mom I’m a virgin”, “so don’t you know that HIV it’s, what do you know about HIV?”, so I was like, “when you have sex with someone that’s how you get it but me I’ve never had sex before why?”….. the information that I had by then was just by sleeping with someone that’s when you can get it, so I never had any intentions that it will come (Chai, F/18)*

For some participants such as Chai, the feelings of shock and surprise were underlined by misinformation/and or lack of knowledge about HIV transmission. Some participants incorrectly assumed that HIV could only be transmitted through sexual intercourse. Despite, many describing learning their status after bouts of serious illness, their HIV diagnosis was still shocking because of the way the illness is perceived and its highly stigmatized nature.

Participants described being angry about their HIV status and directing their anger towards their parents and expressed avoiding communication with their parents for several weeks. Donald describes the anger he felt towards his mother and how it affected his behavior towards her:

> *So after some time, I left home, I went to stay with a cousin, the young sister to my mom… Now the son, yeah, I went to stay with him. So, I stayed like for 3 months with him, I wouldn’t talk to my mom whenever if she calls me, I’ll just reject her call, what, whatever when I go home when she’s there I would not greet her, I’ll just talk to my sisters like that, yeah (M/16)*

Most of the participants that described feeling anger towards their parents had been taking medication for a while before discovering their status, which may have contributed to the significant anger they felt toward their parents.

Participants expressed feelings of doubt over their future, as they felt like their lives were over and worried that they would not be able to achieve the goals or hopes they had envisioned for themselves. These feelings of hopelessness were linked to their fears of dying early as they understood HIV to be a “killer” disease, they felt like being HIV+ was a death sentence.

> *HIV it's a killer disease, so I was just thinking that, I was just thinking that, am HIV very soon am going to die. So I became uncomfortable (Mwape, F/16)*

> *Then you also hear people saying that when you have HIV you're dead so it broke me down [the] first time I discovered, I thought the next day I'm gone, I'm not going to live, I can't achieve certain goals and certain dreams… I thought maybe I'll never be happy, I'll never find, even just associate or even achieve my goals (Dexter, M/19)*

Worries over experiencing an early death led participants to doubt their future as their perception of self and outlook on life had been suddenly altered by discovery of their status. As adolescents develop and improve their cognitive capacities they begin thinking more about the future; therefore, discovering that they have a "deadly" disease may interrupt those plans. Some participants expressed having had doubts over whether they would be able to complete their education, have a career and even get married and be able to have a family of their own. Female participants specifically feared their ability to have children in the future.

> *And I was told being HIV positive, he then set an example of a human being, he brought somebody to say, this is the name of this person, she's HIV positive but she has a negative baby, and I was so shocked, I was like, 'Okay I still have hope, let me just adhere to these drugs' (Sitali, F/20)*

> *The only thing that came in my mind was like, okay I'll be drinking drugs on a daily basis, I'll be having appointments, am I ever going to get married, have kids, no I had negative thoughts about that but, when I came here, like peer educators were educating to say, no you can get married, you can have kids, it's like really normal (Katie, F/19)*

These concerns and doubts led some participants to experience suicidal ideation with one describing several suicide attempts. Participants described feeling like ending their lives because they feared death and felt like they had nothing to live for after learning that they were living with HIV.

> *Then I was told my status but, the first time I just thought my world has ended, my game is over...Thought like, there's nothing that I have, let me just die, there's nothing, there's nothing, I'm not needed in this world, I'm not needed, I'm not important, I'm not wanted in this world, I felt so bad whereby, I cried, I shed tears, I shed tears, I shed tears, I felt that pain whereby, just thought maybe, even suicidal thoughts came into me, i said ah no I should just kill myself, there's nothing I'm doing, so it was really bad, I felt so mental disturbed (Dexter, M/19)*

> *So it was really hard for me to actually accept it. There was one time I tried committing suicide cause I wouldn't live with that (Katie, F/19)*

Some participants described experiencing relief upon learning their HIV status. For some it was because they used to experience frequent bouts of illness or had been seriously ill and discovering their HIV status allowed them to seek treatment and improve their health. Kapa who experienced frequent illness describes how his life changed after learning his HIV status:

> *It [life] changed from bad to good (M/19)*

Others expressed relief because they finally received answers about the medication they had been taking for a while despite asking why and were not told by their caregivers, instead they were often misled.

> *I didn't know why but I was just taking, they were telling me that, ah come and take your medicine, then I was asking them, why am I taking this medicines, at no they are for the headache, what, they were lying, so I had no idea (Alexander, M/18)*

Participants experienced various emotional reactions upon discovery of their HIV status which led them to experience distress and worry as their plans and imagined future seemed suddenly out of reach, which negatively affected their outlook on life.

Psychological consequences of disclosure- *"it was a challenge for them to convince me, or for me to be convinced by them"*

For some participants, the disclosure process led to feelings of disbelief as they found it very hard to believe that they were living with HIV, which affected their ability to accept their status.

> *I never believed cause, by then I just knew that HIV is spread through having unprotected sex, I never knew that it can be spread through from mother-to-child transmission… I just told her [counselor] that I'm not HIV, and I even started saying that HIV is spread through having unprotected sex so, I've never had sex before so how can I be HIV positive. She tried in all ways to make me understand but it didn't…So it was a challenge for them to convince me, or for me to be convinced by them (Lily, F/16)*

Lily's poor knowledge of HIV transmission reinforced her denial as she had difficulty identifying as someone living with HIV, which led her to deny her status for some time.

Feelings of disbelief led some participants to get an HIV test or re-tested to confirm their HIV status. Participants described needing proof of their status and wanting to see the results for themselves which helped them accept that it was true.

> *I believed because I went for VCT (Misozi, F/19)*

> *I had to just get proof, so that I know it's true, maybe he [doctor] was just joking and stuff and that, but then I went to like test and it came out, yeah, I was HIV positive (Ruby, F/19).*

Similarly, participants described feelings of confusion upon discovering their status. They described not understanding how they could have been infected and this caused a lot of them distress. Tengo describes this feeling below:

> *I just felt that weakness which any person has, shocked, how? Why? Questions just came rolling and saying, 'why me?'. I was just better back then and now how come? How come I have the disease. I've read about this disease and I hear that, some they say its deadly, so how come me, am I going to die? Is there a explanation? ….. I experienced a lot of things there, find that I'll just sit then recite verse, how come, how did I get this disease? I'll, I'll think, I'll think, I'll think, but I won't come up with a possible solution (M/16)*

Participants were confused upon discovery of their status because being HIV+ did not align with their perception of self and they were troubled about what being HIV+ meant for their lives.

Participants described feeling different from other members of their family, e.g. siblings as a result of their HIV status. Some participants were the only child in their family living with HIV which made them feel bad as they struggled to understand why and felt victimized by HIV, which negatively affected their identity and sense of belonging.

> *…it was shocking that I'm the only one who had it through my biological dad but when the children with my stepmom, with my stepdad are all negative, so it was like having, how come only me? And these other people are just fine and okay, it also broke me emotionally where everyone who was just talking about my medicine, reminding me, everyone then I was like, why aren't they also sick? (Dexter, M/19)*

However, some participants described feeling different from their siblings because their caregivers were showing them extra care and giving them special attention (e.g. preparing their favorite foods, giving them tv privileges, etc.).

> *And you know there was so much that care, like maybe you're dying, or say you're watching tv everyone they will say 'No, give him he's not feeling well'. You get that thing, it makes you feel, I'm not the, I'm the only one whose not feeling good, just gives you the remote, 'You should watch'. 'What do you want to eat?', ah ok, if maybe everyone is having rice, they'll say 'No, cook for him some something special he's not feeling well' (Dexter, M/19)*

Similarly, some participants described feeling different from their peers as a result of their status. They described feelings of discomfort around their peers as they felt like they were not like them anymore.

> *Cause, you might be with friends and you'll just think like others they are negative and you just have that feeling of you are positive like, you are not one of them (Anna, F/19)*

These feelings of difference led some participants to withdraw from their social circles or limit interactions with peers. Some participants even felt like their peers would be able to tell their HIV status by just looking at them, which made them feel anxious and unsettled.

> *In the beginning like, I had changed slightly, I had withdrawn from my friends, I had pushed a lot of people away because I didn't feel like I was to their level, okay, like I would sit with my friends and then instead of laughing with them like I would just zone out like, I'll be thinking about my own things, like thinking about my own life and how terrible it was and, I was, you can say reserved, more reserved than I was before. I stopped going out like, with friends and everything and then even they realized to say, there' something that has changed in you like, someone has switched a switch in you (Fumina, F/19)*

The feelings described by Fumina are indicative of self-stigma as some participants expressed internalization of the negative beliefs concerning PLWH and felt shame and feared unintentional disclosure of their status.

> *I felt like everyone when I passed they would see he's HIV, like everyone knows….Yeah, like everyone would know, yeah. Like if someone would just look at me, I would just feel they know me…He's so and such ah, like that, so even when people you know in the streets, just there are just certain people who just want to look at you…So for me I took it that, he has maybe he's known, so I felt that discriminatory, self-stigma (Dexter, M/19)*

As described through the two organizing themes of emotional and psychological consequences of disclosure, this global theme explored the emotional and psychological reactions of participants after learning of their HIV status. Discovery of their HIV status was a turning point in the lives of participants which led participants to experience a sudden shift in their identity including their perception of self and their position in the world, leading them to experience doubts over their future, with many fearing an early death. These reactions to discovery of HIV status illustrate some of the difficulties experienced by ALHIV which may make it difficult for them to come to terms with their new reality and have implications for their linkage and retention in care and initiation of treatment.

5.2.2 Coming to terms with HIV reality

This theme describes participant experiences adjusting to their HIV status and what helped them cope. Participants described using psychological and social coping strategies in coming to terms with their HIV status. Coming to terms with their HIV status appeared to play an important role in adjustment and engagement with HIV care and treatment. It also has implications for adolescent identity and sense of belonging. This theme will be presented according to two organizing themes: psychological framing and social support (Table 5-3).

Table 5-3: Coming to terms with HIV reality

Global theme	*Organizing themes*	*Basic themes*
Coming to terms with HIV reality	Psychological framing	• Acceptance • Rationalization • Comparison • Positive mindset • Responsibility
	Social support	• Family • Peers • Support groups • Peer educators • Health staff • NGOs

Psychological framing- *"It is just a circumstance that I couldn't control"*

Participants described using various psychological framing strategies to reframe their experiences which promoted adjustment. Such strategies helped them accept their new reality by helping them come to terms with their HIV status. Participants described accepting their situation and themselves as they emphasized that their status was unchangeable. Ruby expresses the acceptance of her unalterable situation:

> *I just had to accept, there's nothing I can do. There's nothing I can do, I cannot run away from my status (Ruby, F/19)*

Acceptance helped participants move on with their lives and their acknowledgment that they could not change their HIV status promoted adjustment. Participants described integrating their HIV status into their lives and individual identities, Tengo illustrates this sentiment below:

> *…being HIV positive to me is that, I'm living with something which was passed on genetically to me just like, my name in short. Which means that wherever I go I'll always have it, and I just have to compromise with it, and take it to be normal, it's now part of my life, in short. It's part of my life so I just have to live with it, move with it, don't to think about myself in a negative way but, to look for possible solutions in order to cope with the disease because it's now part of my life (M/16)*

Like Tengo, most participants were infected through MTCT and recognizing that they were not responsible for their HIV infection helped them with accepting their status. This suggests that perinatal transmission may facilitate acceptance of HIV status.

In discussing acceptance of their status, some participants mentioned having forgiven their mothers for infecting them with HIV. This forgiveness or blamelessness seemed important for facilitating acceptance.

> *I just took it like, I got it from mom, it was mother-to-child transmission so, I took it, it was not their option to give me that virus, I just took it by, it was either mistake or they do it by deliberate but I just, just forgive them (Chanda, M/19)*

Participants described being comforted by the fact that they are not the only ones living with HIV because upon learning their HIV status many thought they were the only ones living with HIV.

> *I felt as if, I was the only one in this world living with HIV (Misozi, F/19)*

Participants described immense relief after seeing other PLWH, especially their peers which encouraged them and helped them cope.

> *I was encouraged and what I was told is that, even your friends who are here, I was introduced to my fellow young people, that also these guys are in the same situation as you, that's how I relieved from my pain inside (Kabwe, F/16)*

Participants also described that seeing other PLWH who had achieved similar goals or plans that they had for their own lives was also very encouraging. Sitali describes how meeting a woman living with HIV with an HIV negative child was a source of motivation:

> *And I was told being HIV positive, he [counselor] then set an example of a human being, he brought somebody to say, this is the name of this person, she's HIV positive but she has a negative baby, and I was so shocked, I was like, 'Okay I still have hope, let me just adhere to these drugs', and I picked myself up and I'm here today (Sitali, F/20)*

Participants described being comforted by their ability to do anything individuals living without HIV could do. In comparing themselves with individuals not living with HIV they realized that there were no major differences between them and that their HIV+ status does not disadvantage them, they are able to do the same things and lead normal lives like anyone else. Recognition that living with HIV does not limit their capabilities to achieve their hopes, goals and dreams helped them cope.

> *I didn't feel bad about being positive, because even a person who is not positive and I, we are just the same…What is different is just a virus… Yeah, what a negative person can do, even me, I can (Luwi, F/16)*

Participants described maintaining a positive mindset as helping them cope and come to terms with their HIV status. Maintaining a positive mindset or outlook encouraged participants to be hopeful and helped them deal with challenges they encountered going about their daily lives. Tengo emphasizes the importance of positive thinking to avoid depression, which is one of the most common mental health disorders in adolescence (McNeely and Blanchard, 2010):

> *I decided, okay its fine now since I have this disease let me focus on things which I can do, not focus on the disadvantages which I have because, if I focus on the things which I cannot do, this will lead into depression, I'll be depressed so I decided to move on in short (Tengo, M/16)*

A few male participants reported commitment to their treatment in order to take care of their family, reflecting traditional gender norms in which men are generally expected to care for their families and women are expected to be dependent. They described this responsibility to care for their families as helping them cope with their HIV status and engage in treatment. As eldest sons, Donald and Chilando describe their responsibility to care for their sisters in the quotes below.

> *I'm the only son, child to my mom, yeah. My dad has been married 3 times, but I'm the only child, so I live because I want to look up to my sister's.If they need anything I'm always there for them. They need help with me I am always there to help them in any way. I'm always there to help, anyone in the family (Donald, M/16)*

> *After some time my mom passed on because she stopped taking the medication, mhm. Then that same year, my dad spoke to me saying, no these things happen, you can't control them, you're the only elder son that I have, I've got two elder sisters but I'm the oldest son in my family. Even though you might have these elder sisters, you're still the man you have to take care of the things, everything so, I thought about it then, since then I've been adhering to the medication (Chilando, M/19)*

Chilando had experienced issues with coming to terms with his status which would affect his adherence but after accepting responsibility for his families wellbeing he came to terms with it which facilitated his engagement with treatment. Participants used a variety of emotional coping strategies to frame their new reality and facilitate adjustment.

Social support- ***“when I’m going through emotional distress they really comfort me”***

Participants described receiving various forms of social support including emotional and informational from various sources, including family, friends, support groups, peer educators, health staff and NGOs. Participants described receiving emotional support in the form of encouragement and motivation from family that helped them overcome difficulties and challenges in coming to terms with a future living with HIV. Caregivers played a significant role in emotionally supporting participants post-disclosure and provided role models for some participants which encouraged them to adhere to their treatment. John describes the encouragement he received from his mother that motivated him and helped him come to terms with his status:

> *…my mom was one of the biggest players because, she actually told me, it’s not a physical obstacle, it’s just something we all have, you can’t know that you got it until you get a test, so if you have it it doesn’t mean no you won’t get a job, you won’t get married, you won’t do that, you won’t do that, nah… she initially told me, it was not gonna be an obstacle for me, as long as I just take the medication, do what the doctors tell me to do, and just be confidential with it (John, M/19)*

Peers play a significant role in the lives of adolescents and their support is crucial for adjustment during adolescence. Participants described receiving emotional support from friends. This included encouragement and motivation, including accompanying them to their clinic appointments.

> *I’ve found really good friends, true friends than the friends that I even had before and I just say I feel nice or happy when I’m surrounded with people who are like me cause at least they get me, they understand me…..Cause along the road I was… I thought I was alone so along the road I met people who actually helped me…We would talk, they would also say no this is wrong this is right this is this…. It’s like they make it even easier cause you’re with them, you can even talk about it and not be judged than being with negative people who would actually judge positive people for things*

> *they don't even know… So I can say I mostly surround myself with positive energy and positive people around me cause at least they know how it is…Yeah it helps me push forward with just how we talk and the support they give (Bianca, F/17)*

Instrumental support in the form of treatment-related reminders from family and friends was also described as a facilitator of adherence and retention in care. Participants described receiving medication reminders from various members of their family, including immediate and extended. These reminders were especially helpful when they initially began ART however, some participants still relied on them. Chansa describes her reliance on her mother to support her medication adherence:

> *Mostly how I take my drugs is that mom is the one who reminds me, actually she even gave me a curfew, that I should be home early before that time… 20 hours, so I have to be home early at least. So by 17 I have to be home after school (F/16)*

> *They would set alarms on their phones also. They would make sure they have an alarm and they would even whenever their out am home and they'll call 'Its 20hrs have you taken?' I'm like 'Yes', the other one calls 'Its 20hrs have you taken' ... 'Yes'. And then I could say umm they would also push me to come for appointments cause my mum was the one who used to drop me all the time I would come in here with mum and everyone will be like 'You're a big girl you need to stop coming with your mum'. And my mom will be like 'She's my baby I need to see what's happening'. So, I can say my mum, my mum and my dad are the reason [engaging with treatment] (Bianca, F/17)*

Participants described receiving adherence reminders in the form of phone calls and messages from friends and romantic partners.

> *I've got friends to text me to tell me, oh 'you have to take your drugs so if I were you do it right now' and stuff like that (Chisha, M/19)*

> *…he [boyfriend] understand my situation mostly, he even calls me to say, Chai have you taken your medicine, ah okay yes I have, so it's normal for me, I'm very much free (Chai, F/18)*

Support groups were described as another important source of emotional and informational support. Through participation in support groups and workshops, participants described being encouraged and gaining knowledge about HIV/AIDS and managing/living with HIV, e.g. adherence information, lifestyle and disclosure. Participants built relationships with fellow ALHIV which have important implications for adolescent identity and sense of belonging, e.g. acceptance by peers. Charles describes the emotional support he received from participating in support groups:

> *At the clinic we have the support group. We usually meet on Saturday with my fellow adolescent, whereby we discuss positive living, adherence to medication, um stigma, stigmatization, a lot of topic we also discuss with my fellow girls… So we also discuss about how to disclose your status, the steps that you need to take by disclosing your status (Georgia, F/19)*

Clinic programs also provide a space for participants to meet other ALHIV and make friends in a comfortable and safe environment. Chanda describes the relief he gets when attending clinic programs:

> *But here I found, I found it comfortable cause I know everyone who is found here is positive, so I just found it comfortable cause, when I come here mingle with friends, feel comfortable, but at home I pretend as if I'm negative but I'm not (M/19)*

Participants also described receiving emotional support from peer educators. Peer educators are a unique and important source of support for participants.

> *…when I'm going through emotional distress they really comfort me and give me the best information that I cannot ask from my mom even though we're close. I would go to my friends my age, who are peer mentors of course and I would explain to them and then they would just give me a sense of, okay, yeah this is the right way, like they will just direct me and then, yeah (Fumina, F/19)*

Fumina describes how she turns to peer educators when experiencing difficulties. Being ALHIV themselves, peer educators are seen as relatable and participants felt comfortable opening up to them.

Participants described receiving emotional and informational support from health staff in the form of encouragement, motivation, treatment and lifestyle advice. Some participants emphasized the kindness of health staff and the positive relationships they had with them. Through the persistent efforts of health staff participants were encouraged to accept their status.

> *They're friendly, they can even make you feel comfortable with them, you can say anything (Anna, F/19)*

> *With the doctors and nurses they've given me all the information I need, all the support I need, I've found people who I could call my family here… people who've actually warned me and told me, oh you shouldn't do such, if you want to drink alcohol don't drink too much cause you know you might be suppressing drug and then the virus will increase and stuff like that. So, I would say the doctors and nurses here have really helped, they've given me help in my diet, my workout routine, I just have to live my life (Chisha, M/19)*

Participants described receiving emotional and informational support from NGOs. NGO programs provide participants with encouragement and information about living with HIV.

> *I want them to be calling us every time, so that we should be encouraged, maybe we should be coming to play around like everyday here, then they shouldn't stop encouraging us, supporting us to take our meds and teaching us how to take our meds (Naka, F/19)*

Participants described enjoying participating in the programs and social activities arranged by NGOs. These organizations play an important role in equipping participants with skills, as described below by Georgia:

> ***Georgia**: Uh we have a computer lesson, uh there is, the library where we come to study, to do our homework. We also do ma gardenings, how to make sani towel pad, yeah, and even sports activities.*
> ***Interviewer:** And how long have you been coming here?*
> ***Georgia:** Um, I started coming here last year.*
> ***Interviewer:** And you enjoy coming here, the services that they provide?*
> ***Georgia:** Yes, I enjoy, I enjoy a lot (F/19)*

Participants also felt encouraged through their involvement in such activities. Which as described by Naka below may also serve as distractions from any worries or difficulties they may be experiencing.

> *It keeps us going, when we stay back home we think a lot, why we take our meds something like that, so at least when we come here, we play around with friends, watch movies, that encourage us (Naka, F/19)*

As described through the two organizing themes of psychological framing and social support, this global theme explored how participants overcame some of the difficulties in coming to terms with their HIV diagnosis. Participants used various psychological strategies and received social support from diverse sources to help them adjust and come to terms with a future living with HIV and engage with HIV care services. Coming to terms with their HIV status significantly influenced linkage to care, retention in care and adherence to ART.

5.2.3 Drivers of rejection of treatment

This theme examines the challenges faced by ALHIV with engagement in HIV care. Participants described diverse challenges with treatment and care, highlighting major barriers to HIV care engagement faced by ALHIV, including managing adherence in the context of everyday life activities. These challenges may lead to a rejection of treatment as they make adhering to medication and seeking/engaging in treatment increasingly difficult, which may negatively affect the development of healthy behaviors which is critical during adolescence (Viner et al., 2012). This theme will be presented according to three organizing themes:

ARV formulation contributes to medication non-compliance, everyday life events affect adherence and challenges to accessing care/treatment (Table 5-4).

Table 5-4: Drivers of rejection of treatment

Global theme	*Organizing themes*	*Basic themes*
Drivers of rejection of treatment	ARV formulation contributes to medication non-compliance	• Size and taste of ARVs • Side effects of ARVs • Unknown reasons for medication • Misinformation about ARVs
	Everyday life events affect adherence	• Busy/pre-occupied with tasks • School-related activities • Unexpected/irregular events • Leisure/social activities with peers
	Challenges to accessing care/treatment	• Distance to clinic • Inconvenient clinic hours • Long waiting times • Clinic infrastructure • ART stock-outs • Unprofessional/unkind health staff

ARV formulation contributes to medication non-compliance- *"I still feel the nausea"*

The formulation of ARVs, particularly their size and the experience of side effects were described by participants as challenges to their adherence. Participants described being put off by the large size of their medication, which led some to not comply with their treatment, e.g. throwing their medication away. Mwape describes how the size of her medication negatively affected her adherence:

> *I felt I was feeling bad, sometimes I would just get the medicine throw it away and lie that I've taken the medicine… I was having challenges when swallowing, it was like bigger, could not manage to swallow, so I used to throw them away (F/16)*

Side effects of ARVs were also described as challenges to participant adherence. The duration of these side effects varied with some participants reporting experiencing side effects for a matter of days, weeks or even months. Commonly mentioned side effects included bitter taste, dizziness, insomnia, rashes, nausea, night sweats, vomiting and weakness. Most participants were not currently experiencing any side effects however, a few were still experiencing some difficulties as expressed by Sitali below:

> *…when I would take [my pills], I'll feel that bitterness and yeah. At a point I used to even hide them like, under my bed they would pile up a lot… Also the side effects, I just didn't like getting sick anyhow, I thought that even not taking them I would be much better, cause once you'd express the side effects for like 2 weeks, others it will even takes a month. For me it took 2 weeks, I would feel weakness and then, um, like, um, nausea, like even till now I still feel the nausea once I take the drugs, like I feel like puking, so the side effects will drain me down (F/20)*

Many participants described being unaware of the reasons why they were taking medication until their HIV status was revealed to them. However, being unaware of the reasons for taking medication affected their adherence of a few participants for some time as they described not wanting to take medication without knowing its purpose.

> *I remember there was a month, a month or a week, where I didn't actually take my drugs every time she [mom] will tell me I'd just get one tablet pack it somewhere, then at the end of the day or maybe going to school I would throw it out. I think the same curiosity I had of why am I still taking this drugs, cause I noticed the drugs that I take for my HIV and then there were those maybe when I got sick of flu and malaria then, I would ask myself like how is it possible that I'm stopping to take certain drugs but I'm still taking this same drug, so for the moment I thought like, ah I don't know I think my whatever sickness I had is over so I'll just stop taking this drugs (Chisha, M/19)*

> *Because I was like, sometimes I wouldn't take them because, how can I take medication if I don't know what's wrong with me (Kapoka, M/18)*

Some participants described misinformation about ARVs from the community and peers as influencing either their decision to begin treatment or their adherence to medication. Below Georgia describes how misinformation from the community resulted in her delaying ART initiation and Mwela describes how misinformation from her friend disrupted her adherence for a period of time.

> *…because um, I used to heard some challenges in the community to say, 'No when you start taking your medication you'll be feeling dizzy, you be having nightmares, dreaming about ghosts, so I was scared', no me start dreaming about ghosts or some other issue, no you'll have… ah I don't know what they were saying in the community that's what made me to do that [delay ART initiation] (Georgia, F/19)*

> *Um, I was at a boarding school, and I had this certain friend who told me that the father is also on the same medication, and the father told her that these medicines are demons, so I didn't like do a research I just went on believing like what she said, then I just definitely stopped (Mwela, F/19)*

Medication-related challenges negatively affected adherence among participants. Difficulty ingesting the ARVs due to their size, the experience of side effects and misinformation about ARVs contribute to medication non-compliance.

Everyday life events affect adherence- *"it's very difficult for you to take your drugs whilst you are at school cause it's very uncomfortable"*

Participants described their involvement in daily life activities such as studying or cooking as a challenge to their adherence as it leads them to take their medication late or miss their doses entirely. Chansa describes how her pre-occupation with chores and other tasks affects her adherence:

> *Some of the challenges is that sometimes I get busy, sometimes you find that I'm doing something so it grabs my attention and forget to take, but I don't miss a lot of days, except 3 days at least, that's the maximum of numbers. So what happens sometimes you find that I'm tired I just want to sleep then I'll forget I'll realize next morning, that's what happens….something grabs my attention, maybe cooking or sometimes I just sleep, I forget (F/16)*

Adolescents spend a significant amount of their time in school which has implications for their engagement in treatment and care. Most of the participants were enrolled in secondary school at the time of the interviews and described their engagement in school-related activities as a challenge to their adherence. Participants described how coming home late from school sometimes affected their adherence:

> *Sometimes tuitions [extra lessons], if I take medicine 20, attend tuitions maybe 20:30 you're not yet back home, that's the reason, I just miss (Chijika, F/19)*

For some participants, the time they have to take their medication coincides with preparations for school in the morning or school hours during the day. This would sometimes lead them to forget to take their medication and/or sometimes missing it to avoid arousing suspicion amongst their peers.

> *Uh mostly it would due to school cause sometimes you find out that the time you're supposed to take your medicine you'll be in class, which is very weird that each and every time at a certain particular time you have to ask for permission to go out for you to take your drugs and it's very difficult for you to take your drugs whilst you are at school cause it's very uncomfortable, lots of people would be watching you, and sometimes you do that maybe you forgot the time you can take the drugs and when you realize it's already late, you can't take the drugs (Tukiya, F/19)*

Unexpected or irregularly occurring events, e.g. unexpectedly going out with a caregiver, spending a night at a relatives, or going to a camp, similarly affect adherence. These events do not occur frequently but they were described as affecting participant adherence. Lily describes how her attendance at camps hosted by her church negatively affects her adherence:

> *I do manage, but maybe I'll be late to take my drugs, about 10, 15 minutes and that's challenging… Cause there are a lot of activities which go on, so maybe I may forget the time. I'll be thinking that it's 19 but it's already 20, so that's the challenge when I go on trips (F/16)*

Participants also described engagement in social or leisure activities as a challenge to their adherence. They described being busy or preoccupied with certain activities inside or outside of the house, e.g. socializing with peers, which often leads them to forget to take their medication or to take it late.

> *Sometimes I forget, when I am with my friend then we are somewhere, but we are far from home, if I knew that ah 20 hours it is already so, I just said ah I'll fix tomorrow, the day it will pass then I must drink (Alexander, M/19)*

Similarly, alcohol consumption was described as affecting participant adherence, with some participants expressing the need to choose between adhering to their medication or consuming alcohol at social events. Consumption of alcohol with ART can have negative consequences, as described by Sitali in the quote below.

> *…they say you can't like, you can't take the drugs while drinking, then your friends tell you and you're like, ah you're having a party pa Chicago's, I bet you know Chicago's, do you know it? Just say, we're having a party Chicago's, then you decide should I take the drugs or should I not take the drugs (Chanda, M/19)*

> *Adhering, it's in general, you'd find I'll go for parties and stuff, my time passes, I forget to take them. Then the other part is that, um, the mixture of drug, um, alcohol and the medicine sometimes would affect me (Sitali, F/20)*

Participants described the difficulties they experience with juggling the various demands on their time and its impact on their medication adherence. Engagement in everyday life activities, such as household chores, school-related activities, extracurriculars and maintaining a social life affects participant adherence.

Perceptions of treatment failure

In discussions about medication adherence, some participants expressed a fear of being seen to be nonadherent due to the stigma associated with less than perfect adherence. This was expressed in moral terms in their narratives where they understood that adhering to their medication as instructed is the "right" thing to do and not adhering is "wrong". If participants missed taking their medication they would not reveal it to their caregivers out of fears of being reprimanded.

> *I was so tired, I was very tired, and we were going to the overnight at church, so I just reached home, removed my clothes and my friend came, we were just busy, I went, and since mom, the one that I'm living with, she got used to say okay, she takes the medicine alone by herself, yeah she takes it of herself so, even her she didn't even notice anything, so I just went, so that time missed but I never told her cause I know that if I told her, ah she could've shouted at me (Chai, F/18)*

A few also described experiences of being scolded by both caregivers and health care providers for episodes of nonadherence and/or suspected nonadherence. In the quote below Mwape and Tukiya describe being scolded by doctors for non-adherence and suspected non-adherence and Charles described being scolded by his parents when they discovered he had not been adhering to his medication.

> *The doctor told me, you should not do that, it's bad manners just take your medicine otherwise, they take me to the, I don't know the place [sick ward] they say, see how your friend are, then you're like, you're fine then you're throwing the medicine, you become also, you'll very soon be here, then that's how I stopped (Mwape, F/16)*

> *I've had a lot of challenges. Like sometimes they give you the drug, they don't adhere to your system, like I remember the last time when I found out that my viral load was high, and like the doctor was like quite mean to me, he was like, 'you're not adhering to your medication and seeing your viral load it's getting high, which means that you're getting re-infected what's wrong with you', it's like I don't know but I've been adhering to my medicine and he was like, he said something mean to me he's like, if I put you on this drugs, if you don't adhere to it I don't know what will happen next (Tukiya, F/19)*

> *But then one day, he actually found the stack, like the stash of medicines I never used to drink, yeah, I was scolded, yes, by mom, mom and dad. So it was like, they attacked me from all angles. So they were like you're so stupid, drink it your medicine, why aren't you drinking your medicine, you'll die (Charles, M/17)*

Participant narratives demonstrate that treatment failure is stigmatized in both the home and clinic contexts, and that participants fear being conceptualized as non-adherent.

Challenges to accessing care/treatment- ***"some of the doctors are really mean and rude"***

Participants described challenges with accessing treatment and care services. Most of these challenges related to their experiences at clinics, either coming for appointments or participating in clinic programming such as support groups and/or workshops. There was some variation in the challenges experienced by participants based on the type of clinic attended.

Participants described caregiver disbelief and/or denial of their HIV status as a barrier to linkage to care, which for a few resulted in delays in treatment initiation and the experience of poor health.

> ***Bianca:*** *…he tested me, and he told my mom to say, 'Yeah it's true, you just now have to deal with it, it's true and she needs to get on medication'. And that was in I can say June-July and my mom said, 'Okay she will' and we didn't go to the hospital after that, we never went.*
> ***Interviewer:*** *How come?*
> ***Bianca:*** *Um, my mum didn't like the thought of me being with HIV cause I once overheard them saying should we buy plane tickets to go see TB Joshua so that he could pray for me and then, next thing she kept on asking if those things that people put on newspapers to say 'cure for HIV' she kept on asking if it's real if it works. And then after that I could say every morning around 5 we would go to the small room that we have, it was my mom's prayer room then she was like, 'This is our prayer room so we should start praying every morning and it will go away' and we started praying every morning at 5 to 6, 5 to 6, every morning until I could say I got fed up. I was like there is no hope. And then my mom kept on saying "no, no, no" and I'm like deal with it, I have it. Until October then she's like, let's go get tested again. And we got tested and our doctor said "Her CD4 is okay, viral load is a bit okay, but we have a problem cause she needs to be on medication immediately cause her liver is failing" and so um my mom took me the hospital and she got me tested again. And then they were like 'She needs to be on medication immediately'. So I had to go on medication immediately (F/17)*
>
> *…the first time mom brought me for testing, but when the results were positive she didn't believe so she didn't want me to come to be put on treatment, so I had to come again alone, and that's when I had to test again, when I came alone to test, cause I also didn't believe then I discovered I was HIV that's how here a healthy care giver helped me and put me on treatment and talked to my mom that's when she agreed that I should be put on treatment (Kabwe, F/16)*

Distance to clinics and the associated costs of transportation were described as a challenge to attending clinic appointments and participating in clinic programs. Distance to clinics was especially challenging for participants of low-socioeconomic status.

> *I miss appointments because of no transport (Martha, F/20)*

> *…it's not easy cause, I have to look for transport coming here like, go come, then like, due to the increase of fuel, even the bus fare it's also increased, it's also a challenge. So, that's it. It's far yeah, home it's very far (Julius, M/19)*

Similarly, participants described inconvenient clinic hours as a challenge to attending clinics and taking part in programs. Clinic operating hours are often during the day when adolescents are attending school or have extracurricular activities e.g., tutoring. As a result, some participants report having to regularly miss school and programs to attend their appointments which may affect their academic performance.

> *I skip, like today I've skipped… Sometimes you find that uh at school they were learning maybe a critical subject or they have just started a new topic and you weren't there so, for you to catch up sometimes, it takes me some time (Tengo, M/16)*

> *Am in Grade 12, I must study. Saturday's like this time, I was supposed to go at school for extra lessons (Chibesa, M/19)*

Support groups where ALHIV meet and engage with their peers and learn information about HIV are important sources of support for adolescents and have been found to enhance treatment and improve quality of life through equipping individuals with coping skills (Bateganya et al., 2015). But the hours that some meetings are held were described as a barrier to attendance. Lily describes how the time that support programs for youth are held prevents her participation:

> *… some of them like the youth friendly corner, it's, they meet every Friday around 14, then 14 that's the time we knock off at school. So it's a challenge… (F/16)*

Long waiting times is another challenge to accessing HIV care services. Participants describe spending hours at the clinic which is especially challenging for adolescents who have to take off school or engage in other productive activities, including extracurricular activities. Patients can spend a whole day at the clinic, taking up time that they could've used more productively.

> *…there was this clinic we used to go to, there were long queues, I just didn't like it. Like, if this is how I'm going to spend my life, going to the clinic almost every 3 months, going to spend long hours at the clinic, I just, it's one of the things that just set me off like no noooo, I can't be doing this every 3 months, 1 month, just going to stand in a line, long hours just to be given the medication or be treated, I just didn't like that. And the first time I went there, we went around, uh, was 7, sorry we reached there at 6am and we came out there around 19 hours. And ah, for me that was, mh mh, no (Chilando, M/19)*

The long queues at clinics are discouraging and as Chilando described may negatively affect retention in care. Additionally, participants also described having to arrive early, often hours before the clinic opens in order to form a queue to facilitate the running of the clinic and to be among the first to be attended to.

> *Okay my experience is like, for example like today, okay, these days many days, I come early to this clinic, but today I was late, so I found many people there, so that was my experience. If there are many people there, you can't go then fast home, need to be early to this clinic so that you could go first, they say first come first serve so the one who comes first is the one whose be seen, who is served, meaning this my experience, so I was, I always come just early (Alexander, M/18)*

As a result of long queues, some participants expressed worries about transitioning to adult care. Adult clinics were described as having even longer waiting times than adolescent ones and participants expressed unease about having to go there for treatment.

> *…they told me that you start preparing yourself to be coming with adult. Like on the day for adults, it's very bad. There are lots of people like, if you come here early as 6, you'll find yourself that maybe you're even close to being the last one, and you've just come here at 6, and due to many people sometimes they even steal your stuff like, cell phones and some money (Tukiya, F/19)*

Poor infrastructure, including uncomfortable seating areas and unsuitable shelters for waiting clients were described as making clinic visits burdensome, especially since participants often have to wait a while to be attended to. Unsuitable shelter also contributes to overcrowding at congested health facilities. These challenges were described by participants attending Clinic C but were also observed during fieldwork as a challenge for Clinic B.

> *…those chairs, they are not, they are not real, they need chairs like this for example, if you sit, you feel comfortable. Even the building, the what, the bigger shelter, the people they come many people, so sometimes you find that the shelter it will be small, then people will be many, some of them they'll be outside (Alexander, M/19)*

ART stock-outs were also described as a barrier to treatment engagement among participants attending Clinic B and C. When clinics experience stock-outs participants describe often being given less than their usual supply of ARVs. For example they may be given one month instead of three months' worth of medication. This makes retention in care more challenging as it requires more frequent clinic visits which is especially challenging for school going adolescents and those already experiencing challenges accessing health facilities.

> *Sometimes there are times whereby the medicines not enough so we are given a short period of time to come back for appointments, and the drugs are not enough. Example maybe if today is your appointment, then you're supposed to come within a month but they will have to share that drugs and maybe give you a few and give a few so you will have to come back again within a short period of time, like 2 weeks, so that's a challenge (Kapila, F/17)*

> *I would like just the government to, just bring for example, more ARVs to the people, you find that sometimes the ARVs they get, they not manage all the people, they, sometimes they just get few, find a person has come for an appointment, ah there's no medicine just get one bottle come the other month, so I think they need just to bring us more ARVs for the clients (Alexander, M/18)*

Negative interactions with health staff as reported by participants has the potential to significantly affect adolescent attitudes towards treatment and their care seeking behaviors. Participants attending Clinic B described poor professionalism among health staff, including staff turning up and/or starting to work late, spending a lot of time chatting with coworkers and/or taking long breaks while patients were waiting to be seen. It was also described as contributing to long waits at the clinic and affecting access to ARVs.

> *When they come, they didn't start working by the time they come, they just chat first, after they finish chatting, that's when they start working (Luwi, F/16)*

> *I would love the government to help out and intervene because friends, some of them when they come for their appointments they're not given medicine. You'd find that people come here and the doctor maybe has gone somewhere and they are waiting for the medicine so, and they've delayed to give them medicine so, they just get upset and leave the place without getting medicine because of just waiting for the doctor too long (Kabwe, F/16)*

Participants attending Clinic A and B described experiences with unkind health staff including being mistreated, shouted at, and humiliated. Bianca highlights that negative behavior from health staff sometimes prevents adolescents from speaking up, as they fear adverse reactions from health staff which can negatively influence their treatment and wellbeing.

> ***Interviewer:*** *… are you happy with the care that you get here?*
> ***Bianca:*** *Yes, but I can say some of the doctors are really mean and rude.*
> ***Interviewer:*** *So what you would change about it is the attitude of some of the healthcare workers?*
> ***Bianca:*** *Yeah. Cause you'd be… ok you'd walk in you walk out you walk in they shout at you 'What do you want!'… Yeah, they're like that rude. Like whereby we even fail to say things we just be like 'Eeee they will say this so you say on our behalf' and I'll be like ok, yeah. There's that.*
> ***Interviewer:*** *So you don't feel comfortable saying everything because you're worried they'll yell at you?*
> ***Bianca:*** *Yes (F/17)*

Negative interactions with health staff was also described as negatively affecting adolescent access and utilization of health services.

> *Others complained that some nurses are rude, just according to them. Complaining that nurses were rude, are not social and they were being commanded, yeah, so we took up a step to talk to the nurses and everything else, and we're yet to hear their responses from the adolescents if they've improved but, that was the main issue, where adolescents didn't even want to come for appointments… Yeah so, you'd find adolescents would get discriminated and they would even miss appointments because such issues. Where some of them started defaulting, others even started engaging to sex, yeah, and it even reached a point where because of the caregivers, their complaint to adolescents, that even stopped accessing our services, like family planning, where they can have safe sex (Dexter, M/19)*

A few girl participants attending Clinic B described being told to stop attending adolescent clinic days and to begin attending adult clinics as they were "too big" or too old. Participants found these experiences very upsetting.

> ***Naka:*** *There was a day that I went at the clinic the pharmacist shouted at me, then I went home while upset, because of what the pharmacist said. I never even got my meds. He was saying that, why have you come on a Saturday today there are adolescent coming, you are too big, you shouldn't come on a Saturday something like that. Then he was using harsh words.*
> ***Interviewer:*** *Okay, so now you can't go on Saturdays?*
> ***Naka:*** *I go, but if that man who shouted at me is around I go back (F/19)*

Challenges with accessing clinics, inconvenient hours, long waiting times, clinic infrastructure, accessing medication and unkind and unprofessional health staff are factors that make engaging in HIV care difficult.

As described through the three organizing themes of ARV formulation contributes to medication non-compliance, everyday life events affect adherence and challenges to accessing care/treatment, this global theme explored difficulties experienced by participants that make engaging with HIV care services challenging. These experiences negatively affect the treatment experiences of participants and may affect their intentions to remain in care and adhere to treatment. Participants described size and side effects of ARVs, lack of awareness of HIV status, misinformation about ARVs, difficulty managing their adherence in light of their daily life activities and challenges accessing and engaging with clinic services. These factors described by participants act as barriers to retention in care, adherence to ART and achievement of viral suppression. Difficulty managing adherence, missing school to attend appointments and not being able to attend support programs due to time clashes, as well as the experience of negative interactions with health staff are challenges that are particularly relevant for adolescents. Support from family and friends, caring and supportive health staff and adolescent friendly health services (AFHS) may help adolescents cope with such challenges.

Experiences of participants with second-line ART failure

Two participants (Donald and Mwiza) in the sample reported that they were currently on third-line ART. They described being switched to this regimen because they had experienced second-line ART failure. Donald had experienced multiple personal challenges including difficulty accepting his HIV status and the death of his mother which led to prolonged issues with adherence and retention in care, including care disengagement. He also attended boarding school to complete his secondary education, where he may not have had received sufficient social support. When he initially found out about his status he was very upset and stopped taking his medication, stopped attending clinic appointments and engaged in harmful behaviors including excessive drinking.

> *I would do things like smoke, drink, what, stuff, a lot of stuff because I never, I didn’t have friends by that time (M/16)*

He disengaged from care for about 1.5 years and upon re-engaging in treatment he had to be put on second-line ART.

> *At first, I was on first-line and then that's when they noticed that their medicines was not, it's not working, that's how they moved me to second-line (M/16)*

And then when his mother passed away he described another prolonged period of disengagement which contributed to second-line ART failure.

> *I just received a call telling me that ah your mom has passed on, I was like what, so after some time I stopped taking my drugs, I wouldn't go for reviews, I started again the same bad behavior, drinking, what, not listening to anyone (M/16)*

The other participant, Mwiza was quite sickly when I spoke with him so I kept the conversation brief. He reported frequently missing clinic appointments and running out of medication which significantly disrupted his adherence over the years and contributed to his experience of second-line ART failure.

> *I missed appointment then the medicine finished (M/19)*

He was of very low socioeconomic status and had not been able to complete his primary education as a result of financial challenges which he also cited as the main barrier to his engagement and retention in care.

> *I don't have no transport money (M/19)*

Clinic staff stated that his frequently missed appointments have contributed to poor continuity of care and lack of clinical evaluations including viral load testing etc., and as a result of his poor health they were discussing moving him to palliative care as there was nothing more they could do for him. Both participants on third-line regimens experienced difficulty coming to terms with their HIV status and faced significant adherence challenges which contributed to their experience of first and second line ART failure.

5.2.4 Management of anticipated stigma

HIV is a highly stigmatized disease and stigma and discrimination negatively affect the lives of PLWH (Rueda et al., 2016). Anticipated stigma refers to the expectation people hold about the likelihood of being stigmatized by others as a result of their HIV status (Quinn and Chaudoir, 2009). This theme explores strategies utilized by participants to manage anticipated stigma and its influence on their engagement with treatment. This theme will be presented according to three organizing themes: avoid unplanned disclosure, blending in and maintain secrecy (Table 5-5).

Table 5-5: Management of anticipated stigma

Global theme	*Organizing themes*	*Basic themes*
Management of anticipated stigma	Avoid unplanned disclosure	• Concealing medication • Taking medication in hiding • Missing/delaying doses
	Blending in	• Lying • Entertaining and engaging in stigma-related behaviors
	Maintain secrecy	• Fear of stigma and discrimination • Fear of status being shared with others • Instructed to not disclose

Avoid unplanned disclosure- *“I take it on different times when I’m with people”*

Participants avoided stigma by avoiding detection of their HIV status. They described avoiding unplanned disclosure of their status by concealing medication, and missing and/or delaying doses. Participants described concealing their medication in different packaging to avoid exposure of their status. For example, a few described concealing their medication in small sachets which are often used to store medications loosely and are easier to carry than pill bottles that are bulky and make noise. Charles described how he used a small Panado (medication containing paracetamol) sachet to conceal his medication when there was a funeral lasting a few days at his home. In keeping his medication in a Panado sachet he avoided potential stigma and discrimination.

> *I just got an idea of getting a medicine, to take in a sachet. You know that ka Panado sachet and stuff…Yes, so that it’s way better than making noise, whatever whatever, because these things they make noise, the tablets… Yes, so I just, I was doing that, nobody was asking no what are those for, whatever whatever, issues like that (M/17)*

Concealing medication was especially difficult for those who attended boarding school.

> *Like, I was at Siavonga so, the drugs I used to leave it at my brother to my father at Siavonga, he was the Head at the school so, that’s where I used to leave the drugs, he used to live nearby school so around when it reaches 19 or 18 something, I used to come out from class, from school, from ma dorms, and I go to my father’s brother to get the medication… I was scared keeping them in my locker, a friend used to search and they can find them so I used to keep them at my uncle (Chanda, M/19)*

In addition to concealing their medication, participants described hiding to take their medication. When at friends’ houses’ or out and about they described excusing themselves and going to a private place to take their medication.

> *… if I'm at my friend's place, I will excuse my friends, maybe I will go in a bath so that shouldn't see what am doing. In that room I'll get and I'll come back as if nothing happened (Bwalya, M/18)*

Participants described missing doses and/or delaying taking their medication in order to avoid unintentional disclosure of their status which negatively affects their adherence to treatment. Tengo describes his difficulties with adhering to his medication when he is away from home:

> *…so you find that you're not free to take your medications so, time passes, sometimes you won't drink at exactly 20 hours, sometimes you drink 21, sometimes you even drink before 20 hours because that's where you have the chance to drink your medicine… When I'm home no, unless if I'm somewhere, maybe a retreat, that's where I have problems with taking my medication because time doesn't allow… it's because I'm with people, because, how can you answer a lot of questions at the same time so, you feel cornered, in short. When I'm with people, yes, it's difficult, that's why I said that, I take it on different times when I'm with people because, that's the time which I am free (M/16)*

Participants fear the potential consequences of disclosure of their HIV status. As a result, they described engaging in self-protective behaviors such as concealing their medication and missing or delaying taking their medication to avoid unplanned disclosure of their status.

Blending in- *"I just tell them that's the way I am"*

Participants described lying to peers in response to questions related to their medication including side effects and to excuse their absences from school.

> *I was talking to the doctors in there, I was telling them that usually I have yellow eyes when I take the medication, and each time I'm at school guys will be asking me, 'why are your eyes yellow?' It's because of the medication, because I can't tell them it's because of the medication, they'll start asking more questions ah, I just tell them that's the way I am (Chilando, M/19)*

> *When I know that maybe tomorrow I'm supposed to go to the hospital, supposed to come here, I will just say, I will just make up an excuse, 'I'm not feeling well, I won't come tomorrow', sometimes no, 'I'm going to visit someone, its urgent', 'I'm going to a funeral', such things, to make them believe. So that, if the following day I won't show up, they will already know (Tengo, M/16)*

Participants described entertaining and engaging in stigma-related behaviors with peers to blend in. They described making or laughing at jokes made by peers about PLWH.

> *…at school, the way people talk about it, I would laugh you know, just to blend in. So, I would laugh, yeah like that, but you just know that these people are lacking knowledge, and usually, my friends I've noticed them, if you try to teach them something and they, seriously don't want it, they'll just start making fun of you (Chilando. M/19)*

Participants described lying and making up excuses when asked about issues relating to their HIV status and engaging in stigmatizing behaviors in order to blend in with their peers and avoid disclosure of their HIV status. Engaging in these behaviors helps them manage the threat of anticipated stigma.

Maintain secrecy- *"they think that when you're playing together you can give them HIV"*

Fear of experiencing stigma and discrimination led participants to be weary of sharing their status with others. This led many participants to keep their status a secret and not share it with their peers or friends.

> *When I tell a friend, that am HIV positive, some friends may even dump you because they think that when you're playing together you can give them HIV… And they can even laugh at you, don't speak with you, they can even make you down (Zuba, F/16)*

The fears and anxiety surrounding disclosure were heightened if they had already experienced discrimination as a result of disclosing their status to someone, as described in the quote below.

> *…am scared to lose some people because, they might think, I don't know, but this is how it is, people never get to stick around when you tell them such things, they'll always run away. I tried telling my ex-boyfriend once, then he left, just because I never, I don't know, just because he thought I wasn't human, maybe or I would give it to him (Katie, F/19)*

> *When I discovered about HIV, that I am HIV um, I was dating this guy and it was so awkward for me to face this guy to say that, but I don't know where I got the confidence and I told him, after I told him he reacted, he was like, I can't be with a girl who is like this and me I'm like that, so it was so hard for me, I was like, how will I face the future, where would I go with this disease (Chai, F/18)*

Participants also described fears of their status being shared with others if they were to disclose.

> *Am scared my friends would start telling anyone that I'm sick of HIV or they would even start bringing up stories and finger-pointing at me that I'm HIV positive (Chansa, F/16)*

Participants also described being instructed by caregivers not to reveal their status to anyone. Pamela describes her mother instructing her to keep her status a secret:

> ***Interviewer:*** *How come you haven't told anybody else?*
> **Pamela***: Because my mom said that you shouldn't have told anyone, this is a family issue (F/16)*

Throughout the interviews, participants discussed the profound stigma attached to HIV/AIDS and PLWH and their worries about being stigmatized. In order to avoid potential negative consequences participants described keeping their HIV status a secret.

As described through the three organizing themes of avoid unplanned disclosure, blending in and maintain secrecy, this global theme explored how participants manage the threat of anticipated stigma. Adolescents are at a stage in their lives when their friendships and relations with peers are very important and their HIV status makes them feel anxious and worried about their status being discovered and the potential negative effects it could have on their lives. In managing anticipated stigma participants described not disclosing their HIV status, concealing their medication, lying, missing and/or delaying taking their medication as prescribed. However, the strategies employed by participants to avoid disclosure of their status sometimes negatively affects their adherence.

5.3 Discussion

The findings from this chapter highlight the experiences of ALHIV along the HIV care continuum, highlighting participant experiences discovering their HIV status; coming to terms with it and coping; challenges with treatment and adherence and the management of anticipated stigma. Discovery of HIV status was central to the experiences of participants and they experienced significant challenges with reconciling their identity with their HIV status (Petersen et al., 2010). They described disclosure as a distressing experience that changed their perception of self, their past and present experiences, leading them to have doubts over their future. It drastically altered or “ruptured” their self-concept which is evidenced in their reactions to learning their status, with other studies reporting similar findings. Participants described experiencing feelings of shock and surprise as they did not expect it (Horter et al., 2017, Kako et al., 2016, Madiba and Mokgatle, 2016, Mutumba et al., 2015b); anger directed at their parents (Galea et al., 2018, Mutwa et al., 2013); doubts over their future including fears of early death (Muessig et al., 2015, Willis et al., 2018); suicidal ideation (Willis et al., 2018, Wonde et al., 2019), relief (Okawa et al., 2017, Madiba and Mokgatle, 2016), disbelief (Horter et al., 2017, Madiba and Mokgatle, 2016, Mutumba et al., 2015b); confusion (Horter et al., 2017, Madiba and Mokgatle, 2016) feelings of difference from other members of their family and peers (Mutumba et al., 2015b, van Wyk and Davids, 2019) and internalized stigma (Willis et al., 2018, Casale et al., 2018). Anger directed specifically towards parents may be a result of delayed disclosure (Phuma-Ngaiyaye and Dartey, 2015, DeSilva et al., 2018, Madiba and Mokgatle, 2016) or means of disclosure, e.g. participants who described anger were not told their status by their caregivers but found out through other means, including workshop participation. Anger at parents was also associated with the length of time participants had unknowingly been living with HIV while their parents were aware (Instone, 2000). Participants described being treated differently by their biological parents from their siblings living without HIV e.g. special treatment as contributing to feelings of difference between their siblings and themselves. This finding contradicts findings in the literature that describe unfair and harsh treatment for ALHIV compared to their siblings living without HIV (Kimera et al., 2020b, Kip et al., 2022). In relation to doubts over their future, this study identified female participant distress over the thought of not being able to have children in the future due to concerns associated with MTCT. Studies among adolescents (Okawa et al., 2018a, Ezeanolue et al., 2006, Van Nuil et al., 2014) and adults (Milford et al., 2021, Cooper et al., 2007, Nattabi et al., 2009, Kanniappan et al., 2008) have found that such fears influence the fertility intentions and concerns of women, highlighting the importance of comprehensive SRH information for adolescents as this was a significant source of stress among female participants. This may be a result of social norms that encourage/pressure women to have children.

Another study found that discovery of HIV status was among the most difficult experiences described by a sample of ALHIV in Zimbabwe in which they experienced significant “feelings of despair and hopelessness, coupled with a sense of imminent death” (Mavhu et al., 2013, p. 5). The evidence suggests that the disclosure of an adolescent’s HIV+ status can be understood to be a disruptive experience (Bury, 1982). Bury (1982) describes being diagnosed with a chronic illness as a disruptive event because it entails the disruption of an individual's belief systems, self-concept and everyday life. Discovery of an HIV+ status, especially at a young age, can have varying emotional and psychological consequences on the psychosocial wellbeing of individuals as adult studies have shown (Payán et al., 2019, Horter et al., 2017, Kako et al., 2016, Bruton et al., 2018). Additionally, living with a chronic illness such as HIV can seriously complicate "the normal developmental challenges of this stage including puberty, sexuality and [the] desire to 'fit' or be 'normal'" (Vranda and Mothi, 2013, p. 20) as described earlier in this thesis (Chapter 1). During adolescence, it is common for individuals to work on establishing their identity, of which the development of self-concept is key. In middle adolescence particularly, adolescents devote attention to developing their individual and social identity (Salmela-Aro, 2011) which can be "seriously complicated by HIV disease" (Vranda and Mothi, 2013, p. 20). Feeling different from peers can negatively affect the wellbeing of ALHIV as peers play a significant role in the formation of social identity which is explained by the increasing importance of peer relationships during adolescence (Salmela-Aro, 2011). The establishment of identity during this period has implications for ALHIV coming to terms with their HIV status as adolescents may have difficulty with adjusting to their HIV status because they may not want to be identified with a highly stigmatized illness. They may have understood themselves to be young and healthy therefore suddenly learning that they have a chronic illness can be distressing (Taddeo et al., 2008). A study among adults living with HIV in the US found that an HIV diagnosis affected the self and public perceptions of participants and challenged their identity as healthy individuals (Baumgartner, 2007).

Adolescents going through middle adolescence begin orienting themselves towards the future and developing long term plans and goals (McNeely and Blanchard, 2010, Salmela-Aro, 2011). This underlines the distress participants felt when they found out their HIV status as they feared dying early and not fulfilling their aspirations. It also highlights the low levels of HIV/AIDS knowledge among adolescents, which has been reported in other studies (Idele et al., 2014, Yi et al., 2018, Badru et al., 2020, Swenson et al., 2010, Dash, 2018). The reactions experienced by participants also reflect that ALHIV may experience internalized stigma after discovering their HIV status which has implications for their wellbeing. Studies among adults living with HIV have shown that internalized stigma is associated with poor HIV treatment outcomes, e.g. sub-optimal ART adherence (Turan et al., 2019, Seghatol-Eslami et al., 2017, Katz et al., 2013, Sweeney and Vanable, 2016, Lyimo et al., 2014); poor retention in care (Christopoulos et al., 2019, Valverde et al., 2018, Earnshaw et al., 2013, Rice et al., 2017); delays in seeking care (Steward et al., 2013) and ART initiation (Logie et al., 2018b); poor physical health (Li et al., 2010a, Kalichman et al., 2009); negative psychological outcomes e.g. depression (Li et al., 2010a, Sweeney and Vanable, 2016, Berger et al., 2001, Lee et al., 2002, Rael and Hampanda, 2016), decreased self-esteem (Berger et al., 2001, Fife and Wright, 2000), increased anxiety (Lee et al., 2002), hopelessness (Lee et al., 2002), self-loathing (Lekas et al., 2006), shame (Sayles et al., 2008, Lekas et al., 2006), psychological distress (Mak et al., 2007, Lekas et al., 2006); decreased social support (Sweeney and Vanable, 2016, Kalichman et al., 2009, Sayles et al., 2008, Takada et al., 2014); decreased quality of life (Holzemer et al., 2007, Fuster-Ruizdeapodaca et al., 2014) and non-disclosure of HIV status (Okello et al., 2015, Overstreet et al., 2013, Tsai et al., 2013). The findings of this analysis demonstrate how individual/personal factors e.g. beliefs and attitudes of participants and interpersonal factors, e.g. relationships with family and peers influence the post-disclosure experiences of ALHIV. Post-disclosure experiences and consequences may differ for horizontally infected adolescents compared to vertically infected adolescents.

Coming to terms with their HIV status is critical for the wellbeing of ALHIV and has implications for engagement with treatment. Some of the coping strategies described by participants have also been reported in other adolescent and adult studies. Participants described acceptance (Myint and Mash, 2008, Lyimo et al., 2014, Okawa et al., 2017); rationalization (Mutumba et al., 2015a, Martin et al., 2013, Silva et al., 2018); comparison (Kourrouski and Lima, 2009, Mutumba et al., 2015a); having a positive outlook (Martin et al., 2013) and social support from family, peers, health staff and clinic programming e.g. support groups, workshops and NGOs (Kumar et al., 2015, Kohli et al., 2016, Chirambo et al., 2019, Mesic et al., 2019, Denison et al., 2015, Mwamba et al., 2018, Mutumba et al., 2015a, Madiba and Josiah, 2019, Lockwood et al., 2019) in helping them come to terms with their status. A study by Okawa et al. (2017) found that a small percentage (8%) of adolescents accepted their status immediately after disclosure, which differs from my findings in which all participants seemed to experience a process that led to eventual acceptance which included a period of adjustment and/or difficulty of various lengths. The finding that forgiveness of mother/parents for transmitting HIV to participants facilitated acceptance of HIV status has also not been widely reported in the adolescent literature.

Also, unlike many studies in the literature, this study found that certain gender norms may facilitate engagement in treatment among men. Gender norms that encourage men to care for their families, especially women relatives facilitated adjustment of a few men in this sample and enhanced their engagement with care contradicting findings from studies that generally find masculine gender norms to be a barrier to treatment engagement in this population (Horter et al., 2017, Mbokazi et al., 2020, Aliyu et al., 2019).

Participants described social support from family and friends as facilitating their adherence. In the literature, caregivers have been found to play a significant role in adherence and engagement with treatment among ALHIV (Mutumba et al., 2015a, Denison et al., 2015, Mutwa et al., 2013, Madiba and Josiah, 2019, Damulira et al., 2019). Participants also described receiving social support from romantic partners in the form of acceptance and encouragement (Fair and Albright, 2012, Nöstlinger et al., 2015, Mutumba et al., 2015a, Lockwood et al., 2019). Support from peers is especially important for adolescents, as they experience the developmental need to belong and crave acceptance from peers which is important for the formation of individual and social identities (Chapter 1).

The findings from this study highlight the importance of social support from friends, especially relationships with peers who are also living with HIV. In support groups, participants described feeling free amongst their peers, making friends and offering each other encouragement and support. Participants were particularly encouraged by seeing PLWH that had achieved similar goals/plans they have for their lives, providing more support for the importance of peer models or role models to support ALHIV. Support groups were seen as a safe space, offering respite from some of the challenges experienced by ALHIV and fostering a sense of belonging (Mavhu et al., 2013, Mackworth-Young et al., 2020). Participants also emphasized the support they received from peer educators who complement traditional health system actors (Mark et al., 2019) as they offer participants a unique level of support due to being of similar age and having similar experiences. In the healthcare context, support groups along with caring and supportive health staff provide much needed support to ALHIV, especially emotionally and instrumentally through supporting adherence (Denison et al., 2015, Nabukeera-Barungi et al., 2015, Ankrah et al., 2016).

In discussing support received from health staff, participants described receiving informational support (Mutumba et al., 2015a, Mesic et al., 2019) that included lifestyle advice in addition to treatment-related concerns such as medication adherence (Lockwood et al., 2019). As described earlier in this thesis, NGOs are important sources of social support for PLWH in resource limited settings (Mercer et al., 1991, Hushie et al., 2016) and participants described receiving support from NGOs through accessing their services and participating in social activities sponsored by them (Lockwood et al., 2019). These findings similarly demonstrate the effects of beliefs and attitudes and relations with family, peers (e.g. friends, fellow ALHIV), health staff and NGOs in ALHIV coping and coming to terms with an HIV diagnosis.

This study highlighted challenges adolescents face with treatment engagement, particularly medication adherence and retention in care. Participants described ARV formulation, particularly the size and taste and the experience of side effects as major challenges to their adherence, with similar findings reported in other adolescent studies (Denison et al., 2015, Ankrah et al., 2016, Nabukeera-Barungi et al., 2015, Mesic et al., 2019, Kunapareddy et al., 2014). Side effects may especially discourage adherence among adolescents when they affect their usual functioning. Being unaware of the reasons for taking medication (Fetzer et al., 2011, Ammon et al., 2018, Biadgilign et al., 2009) and misinformation about ARVs (Galea et al., 2018, Kambale, 2013) were also highlighted as barriers to adherence in this study, emphasizing the importance of timely disclosure of HIV status and basic HIV/AIDS knowledge among children and adolescents. These findings demonstrate how adverse personal experiences ingesting ARVs, poor disclosure and knowledge of HIV may influence adherence.

In trying to lead normal lives participants in this study described missing and/or forgetting and delaying doses of medication often as a result of involvement in daily life activities including going to school, chores, homework, unexpected disruptions to their daily schedules and/or leisure activities with friends with similar findings reported in other studies among PLWH (Ankrah et al., 2016, Madiba and Josiah, 2019, Kim et al., 2017, Nyogea et al., 2015, Mesic et al., 2019, Denison et al., 2015, Kunapareddy et al., 2014). Some of these challenges may stem from struggles with organization and planning ahead to support adherence which could be a result of poor skills related to abstract thinking and planning (Suris et al., 2004), as adolescents are still developing their cognitive capabilities, which may contribute to forgetfulness. Alcohol consumption in the context of socializing with peers was also described as a barrier to adherence. Alcohol consumption is an established risk factor for poor adherence (Braithwaite and Bryant, 2010, Kalichman et al., 2019) and may negatively affect PLWH by suppressing their immune system (Close and Rigamonti, 2006, Braithwaite and Bryant, 2010) and amplifying the toxicity of ARVs (Braithwaite and Bryant, 2010). ALHIV are at increased risk of adherence challenges as a result of alcohol consumption because experimentation with alcohol and other substances tends to begin during adolescence (Close and Rigamonti, 2006). In addition, alcohol consumption increases the risks of engaging in other risky behaviors such as unprotected sex (Close and Rigamonti, 2006, Scott-Sheldon et al., 2017), which has implications for the onward transmission of HIV.

Study findings highlight various challenges faced by ALHIV with adherence and their support needs, demonstrating that managing adherence in the context of everyday life is a significant challenge during adolescence. There are also limited studies on the experiences of PLWH on third-line regimens in SSA, especially adolescents. Most participants in this study were on first or second line treatment however, prolonged challenges with adherence led two participants to be put on third-line regimens (Khan et al., 2014, Pujades-Rodriguez et al., 2010). Social support, including enhanced psychological counselling and financial support may have helped prevent second-line ART failure among these participants as they had experienced significant challenges with adherence and retention care. In a sample of adults living with HIV in India Khan et al. (2014) similarly found that significant challenges with adherence contributed to second-line treatment failure. Despite large numbers of ALHIV in resource limited settings experiencing adherence challenges contributing to second-line treatment failure, there are limited studies examining their experiences and access to third-line regimens is limited (Lanyon et al., 2020, Onoya et al., 2017).

Challenges accessing treatment and care services at the interpersonal and facility level were described by participants. Participants described caregiver denial/disbelief of their HIV status as a barrier to linkage to care which has not been widely reported in the adolescent literature. Barriers at the facility level that have also been reported in other adult and adolescent studies include distance to clinics (including transportation costs) (Tafuma et al., 2018, Chirambo et al., 2019, Wasti et al., 2012b, Madiba and Josiah, 2019, Sanga et al., 2019, Wachira et al., 2014); clinic hours of operation (Mesic et al., 2019, Mwamba et al., 2018, van Wyk and Davids, 2019, Azia et al., 2016, Biadgilign et al., 2009); long waiting times (Tafuma et al., 2018, Martin et al., 2013, Mesic et al., 2019, Sanga et al., 2019, Wachira et al., 2014), poor and cramped infrastructure (Mwamba et al., 2018, Lifson et al., 2013), ARV stock-outs (Moriarty et al., 2018, Gils et al., 2018, Poku et al., 2017, Cluver et al., 2021, Ankomah et al., 2016) and negative interactions with health staff (Mwamba et al., 2018, Wachira et al., 2014, Sanga et al., 2019). These findings indicate that similar healthcare related factors affect the HIV care experiences of different populations and significantly influence retention in care. However, regularly missing school for clinic appointments is a unique challenge faced by ALHIV and can significantly affect educational achievement (Suris et al., 2004). To my knowledge this is one of the first studies to suggest poor clinical infrastructure (physical) as a potential contributor to HIV care disengagement among ALHIV. And the finding concerning crowding in this study was linked to comfort unlike the findings from Lifson et al. (2012) and Mwamba et al. (2017) that were associated with concerns of confidentiality. Findings from this study also indicate that the clinic experiences and challenges faced by participants varied by the type of clinic attended demonstrating the need to pay attention to healthcare factors that may contribute to care disengagement among adolescents.

ALHIV are also typically concerned with being transitioned to adult care clinics. A systematic review exploring transition of care in SSA found the age of transition to vary widely from 13-22 years of age (Dahourou et al., 2017). Participants in this study expressed anxiety and discomfort with having to transition to adult care, as they were concerned with the long waiting times observed at adult clinics. A few female participants described being upset by being told by health staff that they had to come on adult days because they were “too big” for adolescent clinics. This experience was unique to female participants and the health staff telling them not to come were men. This may be explained by the quicker pace of female physical development compared to males (McNeely and Blanchard, 2010, Salmela-Aro, 2011). It also underscores the abrupt and sudden nature of the transition process and the lack of national guidelines and/or standards regarding transfer of adolescents from pediatric to adult HIV care (Abaka and Nutor, 2021).

Participants described interactions with health staff that negatively affected their treatment experiences e.g. unprofessional and rude staff. Poor attitudes among health staff and lack of professionalism, e.g. chatting with one another for extended periods instead of attending to patients have been reported as barriers to linkage, engagement and retention in care in adult studies (Tafuma et al., 2018, Sanga et al., 2019, Wachira et al., 2014, Mwamba et al., 2018, Layer et al., 2014, Ware et al., 2013), whereas positive and supportive relationships between health care providers and patients has been found to promote adherence (Chirambo et al., 2019, Vervoort et al., 2007, Martin et al., 2005). ALHIV regularly spend significant amounts of time at clinics and negative experiences with health care providers can have significant implications for their engagement with HIV treatment and care and health seeking behaviors.

Findings from this study contribute to the limited literature describing the language of “treatment failure” as a barrier to engagement in treatment. Findings show that non-adherence is highly stigmatized in both the home and clinic context due to the moralization of treatment adherence, with similar findings reported in other adolescent studies (Bernays et al., 2017, Burns et al., 2020, Kawuma et al., 2014). However, the language used to describe adolescents experiencing adherence challenges, the fear among ALHIV of being labelled as “treatment failures” and the potential consequences that are associated with it may contribute towards the experience of further adherence challenges if ALHIV are unable to openly share their challenges and the underlying reasons for adherence issues are not addressed. Adolescents reporting these experiences responded by resuming treatment unlike in a study by Burns et al. (2020) that found that some adolescents may push back and refuse to take their medication through acts of defiance.

These findings demonstrate the influence of various interpersonal and institutional factors that act as barriers to engagement with treatment. However, some of the institutional challenges accessing treatment and care services, e.g. distance to clinics, long waiting times and rude health staff seem to permeate across the life course as they have also been reported in studies of adults living with HIV (Chirambo et al., 2019, Wachira et al., 2014, Mwamba et al., 2018).

Stigma continues to negatively impact the response to the HIV/AIDS epidemic. It undermines the psychosocial wellbeing and treatment of PLWH (Rueda et al., 2016, Halli et al., 2017, Turan et al., 2017a, Mahajan et al., 2008) and is a significant barrier to HIV prevention and treatment efforts in Zambia (Walker et al., 2019, Bond et al., 2002). HIV stigma significantly affects the wellbeing of ALHIV and is associated with poor mental and emotional health, non-disclosure of HIV status, decreased social support, poor adherence, and retention in treatment (Abubakar et al., 2016, Mutumba et al., 2015a, Pantelic et al., 2020, Mburu et al., 2014a, McHenry et al., 2017). The experience of anticipated stigma significantly affects the lives of ALHIV with participants in this study describing engagement in certain self-protective behaviors to manage their fears of experiencing stigma and discrimination. These behaviors have also been reported in other studies of PLWH and include concealing medication e.g. storing medication in sachets and taking medication in hiding (Mutumba et al., 2015a, Ramadhani et al., 2018, Okoror et al., 2013, Muiruri et al., 2020, George and Lambert, 2015); lying to protect their HIV status e.g. lying about reasons for medication (Mutumba et al., 2015a, Williams et al., 2017, Roberts, 2005, Ankrah et al., 2016); missing and/or delaying doses (Denison et al., 2015, Mutwa et al., 2013, Rao et al., 2007, Kunapareddy et al., 2014, Kawuma et al., 2014) and nondisclosure (Thupayagale-Tshweneagae, 2010, Abubakar et al., 2016, Mackworth-Young et al., 2020, Fielden et al., 2011).

Adolescents in this sample also described engaging in stigma-related behaviors to blend in with their peers such as making or laughing at jokes about PLWH. This may be explained as a means of protection, as not engaging in such activities with peers may arouse suspicion. This experience was also unique to male participants and has not been reported in the adolescent literature. In addition, some of the self-protective behaviors adolescents engage in may be harmful to their health. For instance, self-repackaging of medication may potentially reduce drug effectiveness (Ramadhani et al., 2018, Muiruri et al., 2020) and lead to virological failure (Ramadhani et al., 2018) and missing doses can also compromise treatment effectiveness (Chen et al., 2017). The self-protective actions taken by participants may also be interpreted as acts of agency within a constrained setting (Mannell et al., 2016, Mackworth-Young et al., 2020). ALHIV employ these strategies to navigate the pervasive stigma of the limiting social landscape (Evans, 2007) in which they are embedded to avoid potential stigma and discrimination from unintentional disclosure of their HIV status, e.g. rejection, etc. (Mutumba et al., 2015a, Hosek et al., 2000, Kourrouski and Lima, 2009, Nyogea et al., 2015, Mackworth-Young et al., 2020). Engaging in these actions may also allow them to maintain a “normal” or more socially acceptable identity that is not associated with illness and/or death (Mackworth-Young et al., 2020). Mackworth-Young et al. (2020) argued that such strategies can be understood to be active strategies within particular social contexts to “control the flow of information, to protect against stigma, and as strategies to manage identity” (p. 730). Studies have found the use of similar stigma management strategies among adults living with HIV (George and Lambert, 2015, Siegel et al., 1998, Rintamaki et al., 2019) and other stigmatized populations, e.g. homeless children (Roschelle and Kaufman, 2004); undocumented students (Yasuike, 2019); recovering drug addicts (Anderson and Ripullo, 1996) and lesbian/gay/bisexual populations (Kalei Kanuha, 1999, Hylton, 2006).

For ALHIV, unintentional disclosure of their HIV status can be detrimental to their identity and belonging, especially during adolescence where peer relations are crucial to identity formation (Reavley et al., 2017). Numerous studies have shown that acceptance by peers is crucial for adolescent social and mental development (Sentse et al., 2010, Rohrbeck, 2003), with rejection and exclusion from peers found to negatively affect psychosocial wellbeing (Buhs and Ladd, 2001, Stanley and Arora, 1998, Storch et al., 2003, Fotti et al., 2006, Miller-Johnson et al., 1999).This evidence illustrates the importance of maintaining control over disclosure and the reluctance among ALHIV to risk disclosing their status to others, especially their peers. There is a paucity of studies examining anticipated stigma among ALHIV however, studies among adults living with HIV have reported significant consequences of anticipated stigma including decreased mental health, e.g. increased psychological distress (Quinn and Chaudoir, 2009), anxiety (Varni et al., 2012), depression (Varni et al., 2012, Turan et al., 2017b); physical illness (Quinn and Chaudoir, 2009); social isolation (Audet et al., 2013); decreased social support (Berger et al., 2001); non-disclosure of HIV status (Derlega et al., 2004, Yoshioka and Schustack, 2001, Sayles et al., 2007, Smith et al., 2008, Wolitski et al., 2009) and suboptimal adherence (Rintamaki et al., 2006, Rice et al., 2019).

Experiences of enacted stigma influenced the willingness of participants to disclose their status in future. Studies among adolescents have shown that enacted stigma is associated with poor mental health, including emotional distress (Mutumba et al., 2015a, Daniel, 2015), loneliness (Kimera et al., 2020a), depression (Ashaba et al., 2019, Aurpibul et al., 2021, Casale et al., 2018, Wolf et al., 2014), suicidal ideation (Wolf et al., 2014), poor adherence (Ashaba et al., 2019, Wolf et al., 2014, Martinez et al., 2012, Mutwa et al., 2013, Mutumba et al., 2015a) and retention in care (Pantelic et al., 2020, Wolf et al., 2014). In addition to not disclosing their status due to fears of stigma and discrimination, participants also described keeping their status a secret per instruction of their caregivers (Madiba and Mokgatle, 2016, Ankrah et al., 2016, Kawuma et al., 2014, James et al., 2018, Daniel, 2015, van Wyk and Davids, 2019). However, nondisclosure of HIV status has negative implications on psychosocial wellbeing and engagement with treatment as it inhibits the development of supportive relationships and makes adherence to treatment more challenging (Hosek et al., 2000, Madiba and Josiah, 2019, Wasti et al., 2012a), which is especially concerning for ALHIV who may benefit from additional social support. Study findings concerning the engagement of participants in self-protective behaviors to prevent unintentional disclosure of their HIV status and nondisclosure, highlight the role of personal beliefs and experiences, interpersonal relations and community factors, e.g. social norms and widely held beliefs in shaping the experiences of ALHIV and underscore the need to address stigma in the wider social environment.

Finally, the HIV care continuum is a useful framework for describing the experiences of ALHIV with HIV treatment and the identification of factors that impede engagement with care. As demonstrated in this study, there are numerous psychosocial factors that negatively affect engagement and retention of ALHIV in HIV care illustrating the need for improvement in the provision of care to this population. The framework also facilitated comparison of experiences within the sample and with other adolescent samples, indicating that ALHIV face similar challenges to engagement in HIV care in resource limited settings in SSA. However, the findings of this study do not shed much light on adolescent decision-making regarding HIV testing, linkage to care and initiation of ART as most of the participants in the sample were perinatally infected and diagnosed with HIV in early childhood. As a result, participants were often unaware of their HIV status until a later stage with caregivers taking initial responsibility for their treatment.

The findings also indicate a few limitations of the continuum of care as a framework to understand the treatment experiences of ALHIV. The framework depicts a linear progression through the stages of treatment however, as demonstrated in the experiences of a few participants with disengagement and re-engagement, the continuum does not reflect the trajectory of experiences of all PLWH, especially those facing significant barriers to treatment engagement (Kay et al., 2016, Ehrenkranz et al., 2021, Tweya et al., 2013). Because PLWH in care may cycle through the various stages and disengage and potentially re-engage at various points (Ware et al., 2013, Burns et al., 2019, Ehrenkranz et al., 2021), it would be useful if these experiences were reflected in the steps of the continuum of care. Ehrenkranz et al. (2021) suggest a revised continuum that considers the cyclical nature of engagement with HIV care services. Such a conceptualization better reflects the reality of the treatment experiences of PLWH, especially ALHIV who are vulnerable to poor outcomes as a result of their stage of development and acknowledges the challenges they are likely to face over the course of lifelong treatment. This conceptualization also encourages increased focus on identifying challenges contributing to disengagement and the provision of targeted support to support PLWH at risk of and currently disengaged from care.

Conclusion

This chapter described the lived experiences of ALHIV aged 15-20 with the HIV care continuum and highlighted experiences with HIV status disclosure, adherence and engaging with treatment. The findings highlight contextual factors that facilitate or impede adolescent engagement along the HIV care continuum and achievement of viral suppression. It also highlights how the developmental changes and challenges experienced during adolescence may compound the stresses of living with a chronic illness in adolescence. Responding to calls for greater qualitative research into the lived experiences of ALHIV in resource-limited settings and exploring reasons for persistent poor health outcomes among ALHIV, it contextualizes the experiences of ALHIV in Zambia and describes psychosocial factors that significantly affect engagement in treatment across socio-ecological levels, including ART adherence and retention in care. Such research is essential to improving the lives of adolescents in resource limited settings, e.g. to improve available services, access and engagement with treatment and care and creating tailored interventions that are responsive to the developmental needs of ALHIV. Findings reveal that ALHIV face significant challenges to adherence and retention in care and highlight the importance of knowledge and social support for facilitating engagement in treatment. This study included the experiences of two participants on third-line ART who had experienced significant challenges with their adherence, highlighting the need for increased HIV counselling and support.

Chapter 6 *"Last year they used to remind me that it's time for your medicine but ah, this year now I'm a grown-up person"*: A life course approach to understanding the experiences of ALHIV

6.1 Introduction

As described earlier in this thesis (Chapter 1) the life course approach studies the influence of biological, psychological, social and environmental factors across an individual's life span that influence their health and wellbeing (Braveman and Barclay, 2009), paying attention to key stages of an individual's development, including life events and transitions (Jones et al., 2019b, Hutchison, 2011). The approach has been widely used to examine factors influencing the development of chronic and infectious disease, factors influencing the development of other sexual and reproductive and general health issues and to assess health disparities. The approach has also been used to examine HIV risk among various populations (Mojola et al., 2015, Ruark et al., 2016, Taggart et al., 2020, Dangerfield et al., 2018, Johnson et al., 2021) however, such an approach has not been widely used to examine the lived experiences of PLWH, especially adolescents (Rosenfeld et al., 2016, Wallach and Brotman, 2018, Moore et al., 2019). This chapter applies a life course approach to explore the experiences (e.g. events and transitions) and challenges ALHIV encounter over the life course (e.g. from childhood through adolescence) and the psychosocial factors influencing these experiences. As the life course approach considers age-related differences and transitions across the life course, the interpretation of findings will highlight some of the observed differences between younger and older adolescents. Building upon the findings of the previous chapter, the findings of this chapter will highlight important shifts, experiences and issues of concern in the lives of ALHIV, and indicate important areas for intervention to support children and adolescents as they age into adulthood.

6.2 Results

The analysis identified eight themes related to experiences and issues/challenges encountered by ALHIV along the life course. These themes include significant life events, transitions, shifts in perspectives and various experiences, highlighting issues of concern for the health and wellbeing of ALHIV.

6.2.1 Early and protracted experiences of poor health- *“I do not want to go back to getting sick”*

Many participants described experiencing acute and/or severe episodes of poor health on and off for years during childhood until their HIV status was discovered.

> *I got sick whereby, I had sores in my eyes, my throat, on the tongue and my lips, in my mouth, so they take me to the nearest clinic, and then they found out I was HIV positive (Mindy, F/18)*

> *Like before I found out that I’ve got HIV I used to constantly get sick, like constantly. Any disease that I come into contact with, I’ll probably pick it up, as in I’ve been sick so many times, there was a time I actually got dysentery, I don’t even know where I got it from then that was the time that my mom decided I should just get a blood test, to get it checked out like, my sicknesses were like back to back, like one minute I’ll have malaria, one minute ill have dysentery, one minute I’ll have this, one minute I’ll have that. Then she was like nah, next you can end up dying because it reached that critical stage that, this is too much for a young person like me (John, M/19)*

> *I had a lot of problems when I was young… I used to get sick a lot, like a lot, uh, a lot of times. I remember my, my father… I just remembered I had a lot of sores, I can’t really remember a lot of things, and I would remember my father was always worried about me, he never liked me going out to play because he was worried I would start getting sick again, but it’s just that the getting sick was too much that one of the doctors decided to say, ‘you should go for an HIV test’ (Chilando, M/19)*

The episodes of prolonged illness impacted the quality of life of affected participants. For example, severe prolonged illness caused a few to miss large amounts of school.

> *Like a great impact cause I remember when first I was infected like, I had several attacks of sicknesses, it was in and out of hospital like really, and my school was affected. Yeah, so it took me like about 6 months, and I was nearly expelled from school like, how can she be absent from school like, mom didn't tell them at first, until after then that's when she went to explain to them, they accepted me back into the school (Tukiya, F/19)*

These early experiences of acute illness were described as significant motivation to stay in care and adhere to medication to avoid experiencing severe illness again.

> *I do not want to go back to getting sick, so I've been pushing myself so that I do not get sick, I am constantly taking my drugs and at the right time (Kapila, F/17)*

> *I just decided I'll just keep on living a positive life with it, and if I start drinking my medicine I'll be healthy and I'll remain strong (Tengo, M/16)*

> *I know that when I stop taking my drugs I'll be, maybe I'll fall ill, I'll die, so just know that it's better for me to come here (Lily, F/16)*

6.2.2 Learning of HIV status a significant life event- *"I just felt like my entire word crumbled"*

Participants described the learning of their HIV status as an event that drastically and suddenly changed their lives. They found themselves trying to adjust to a new and unexpected situation.

> *I just felt like my entire world crumbled. You know like a Cinderella doll? And then Cinderella princess kind of life and then all of a sudden boom, like everything just blacked out (Fumina, F/19)*

> *Being a person who adapts to my situation I was able to get used to be like, okay honestly this is my new situation or my current situation in life, and then I got to accept it (Chisha, M/19)*

Participants described having to make significant changes to their way of life as a result of their HIV status. One such significant change that was emphasized was daily medication taking. This was described as burdensome and especially emphasized by participants who had no experience with regular medication taking prior to disclosure of their status.

> *Like, when they actually showed me the results, they were positive, it was really hard for me, like I felt broken. Cause the only thing that came in my mind was like, okay I'll be drinking drugs on a daily basis, I'll be having appointments (Katie, F/19)*

> *It was hard at first, whereby I wasn't used, whereby I have to go out, if maybe I have to go out with family I have to carry my drugs… Maybe I need to have any occasions my drugs have to be, have to follow me everywhere I'm going (Dexter, M/19)*

A few participants who were not in care at the time of their disclosure but had experienced frequent ill health in early childhood reported that learning their HIV status was life changing because it allowed them to seek treatment and improve their health which in turn positively affected their quality of life.

> *I have got scars, people would ask me, what are all these scars on your body, but since like, those scars were, um, due to the disease but, I didn't know, so we just thought maybe it was some disease, but after they tested it, I started medication, all the sores started healing, now it's just scars remaining, the health has improved (Chilando, M/19)*

Learning of their HIV status also affected the behavior of participants. Some described not engaging in behaviors they used to engage in regularly and without a second thought. In the quotes below Tukiya describes how she stopped having sleep overs with friends and Chisanga describes how he stopped visiting some of his relatives.

> *…at a certain time I have to ditch my friends and I have to go home to take my drugs, so like I stopped the sleeping over thing with friends and like inviting friends to my place like it would just be for a short period of time with my friends then we'd all depart each other (Tukiya, F/19)*

> *I'm not able to like go at visit relatives or whatever. Like no they might figure out that no I'm having such such. You know people nowadays are afraid of this, they think its very bad but I'm learning on how to live with it (Chisanga, M/17)*

6.2.3 Shifting perspectives - *"I feel like I can do anything, I can complete my career, I can achieve my goals"*

Participants described shifts in their perceptions, attitudes and expectations to what living with HIV meant for their lives. Post-disclosure of their HIV status all participants expressed immediate and fear-based concerns including fears of not having a future and were concerned with experiencing premature death. However all participant narratives described a shift to more hopeful and optimistic perceptions of their future.

> *I have this disease, I have to drink medicine, just took it as a normal way of life, something that I have to do. I just decided I'll just keep on living a positive life with it, just took it as a normal way of life (Tengo, M/16)*

> *All you have to do just is adhere your medication, take your drugs cause that's not the end of your life. You just have to take your drugs, go to school, and be what you want to be in future. I know its my life and my future (Misozi, F/19)*

Older participants expressed a gradual acceptance of their HIV status that happened over time and its integration with their identity.

> *So as time went on I understood how it really felt and how many years I've lived with it, so as time went on I accepted it. From there I have actually become confident of who I am cause I can't change that (Katie, F/19)*

> *As for me for now, as I'm like from 20, what's this 2012 until 2019, just been living a great life with my HIV status, yeah, because, it's now a part of me as I said (Felix, M/19)*

6.2.4 Poverty limits educational aspirations- "I even stopped going to school because there was no one to sponsor me"

Several participants were of low-socioeconomic status which has shaped and continues to shape their lived experiences. Regarding education, some participants described being unable to complete their education, either stopping in primary or secondary. Some participants reported losing one or both parents in childhood which contributed to their inability to complete their education.

> ***Interviewer:*** *When did you stop going to school?*
> ***Mwiza:*** *Because my father don't support me.*
> ***Interviewer:*** *What grade did you stop?*
> ***Mwiza:*** *Grade 5 (M/19)*

> *I live with my auntie, my dad and my mom passed away in 2008. After my parents passed away things were very complicated, I even stopped going to school because there was no one to sponsor me at terms of school fees. So my auntie's the one who took me where I used to live with my parents, she's the one who's taking care of me. So since now, I've not yet started going to school (Georgia, F/19)*

These participants expressed their wish for support to be able to return to school.

> *After I wrote Grade 7, then my dad passed on, so I never wrote Grade 8. I admire going back to school (Naka, F/19)*

> *I was in Grade 8, I don’t have school fees. My auntie, the sister to my father, don’t have school fees but I really want to go to school (Solomon, M/18)*

6.2.5 Experiences of stigma- *“I was segregated normally”*

Some participants described experiencing HIV-related stigma in two spheres where they spend/spent significant amounts of time: the home and school context. These experiences contributed to feelings of internalized stigma. Within the home they experienced differential and hostile treatment.

> *I was segregated normally. You see, so, um, you find that she’ll [aunt] buy your own soap, your own face towel, it reached an extent of, um, giving you your own plate, your own cup to drink in, yeah, till um… Cause, um, a doctor from here, um, Dr. Joyce*, yeah she’s the one who came by my place and counselled them but, still it looked like um, she didn’t have that much of understanding still, like, she was still in the denial process, yeah. And having adopted me she felt like, ‘what am I adopting? Am I adopting a person or a sick, something that will stress me’, yeah, very much. So, I started feeling kind of guilty, like I’m the reason why, maybe she’s treating me like that, and psychologically I just started running, shunning away myself from my friends. I felt like, I’m different from them now that I have this disease. I couldn’t socialize, I’ll just keep myself away from them. It really affected me spiritually, everything, cause I couldn’t put myself together (Sitali, F/20)*

> *The time when I was living Central* [province] with my auntie, whereby you find that, she’s not that kind of a person whereby she keeps things by herself, she used to tell everyone, all the neighbors knew that I was HIV positive, so even the way she used to treat me, it was that bad whereby, she’ll refuse to share the clothes with her children, and to share like, to share cups in the family, she used to give me my own cup and my own spoon, yeah it was… Yeah whereby sometimes, I would just [laughs], it’s only from God’s love, whereby sometimes I just like, I wanted to kill myself, commit suicide because, of the things where, what was happening in my life and the way she was treating me (Mindy, F/18)*

> *My grandmom wasn’t treat me well. Because they were saying, no don’t do this with this one she’s positive, so we were sharing cups, me I have my own cups but, for now they have understood, my status, now we are just okay (Luwi, F/16)*

Within the school context participants describe experiencing internalized stigma as a result of incorrect and stigmatizing statements and jokes made by their classmates about PLWH.

> *But at times it would pain me whereby I've removed certain friends, in school whereby they would say, just ill things by then I wasn't fully accept, I had accepted but you just know there's just that hard time, whereby you hear something bad and it breaks you down (Charles/M/17)*

> *Ah, I think, like I'm going to go back to stigmatism, when people hear, when people who are not educated about HIV talk about it, they just think like HIV is death or something. Like as I can remember, I think that was in grade 8 or 9, there were some people talking about HIV but, one uttered some bad words, he just went like, people with HIV are dead, like they are dead people walking, so that actually hurt me, I wasn't cool with it. Yes, so it was like, more like everything he was saying was pointing out to me (Charles, M/17)*

They also experience internalized stigma within the classroom, as they describe teachers spreading misinformation and perpetuating stigmatizing beliefs.

> ***Chisha:*** *I remember I would loathe people who had HIV cause of the false information we were given in schools of um, if you've got HIV it's a death sentence. So I remember staying 2 weeks in my room, asking myself 'Why, why, why', and then when I came here and got the right information.*
> ***Interviewer:*** *So, what kind of things in school did they tell you about HIV that you found out weren't true?*
> ***Chisha:*** *Oh the first one or the main one that's taught in Zambia is if you've got HIV it's basically a death sentence or if you've got HIV you are unlike other people, you're gonna get thin, you're eventually going to die, but when I came here to Clinic A* I was told that there's a difference between HIV and AIDS, they say HIV is a process when I'm taking the drugs and I'm suppressing the virus, while when you have AIDS is when the drugs that you're taking have completely stopped working, now that's when you start thinking of people getting thin, you know they're on their beds they can't do much, so when I got the information from here I was able to process to say, oh so basically what I was being taught is different compared to the pros who have told me what HIV and AIDS is all about (M/19)*

> *HIV, uh it has affected my life in some ways cause, I do feel uncomfortable when I'm in class mostly and the teacher is explaining about HIV then she starts saying, if you have HIV then you'll die early, you see that? I don't feel comfortable and I don't respond much in class, yeah, cause it hurts me. Yes, it hurts me since me I know how it is and how it feels like to be with it, but I think others they don't understand what living HIV is all about* (Chai, F/18)

6.2.6 Shifting responsibility for health and wellbeing- *"now I do come alone"*

Participants described increased responsibility for their health and wellbeing and less dependence on caregivers. This theme will be demonstrated using the experiences of three participants (Felix, Chai and Dexter) to illustrate the shifts in treatment experiences. In descriptions of their childhood experiences participants described caregivers as having an active role in their treatment and care. This included managing their adherence, including keeping their medication for them and observing them take it.

> *I didn't know anything by that time, I was just following, I was like a tail that's following aunty around, like let's go this side, let's go this side because you're sick of stuff (Felix, M/19)*

> *What used to happen is that my sister would put a reminder and I would put a reminder, and my drugs mom had decided to keep them in her room. Every morning she would come to me and tell me drink I want to see you drink your medicine. Swallow, all those things (Dexter, M/19)*

Participants also described caregivers ensuring that they attended their clinic appointments by accompanying them and/or having family members escort them. Some like Chai, describe feeling uncomfortable attending clinic appointments on their own.

> *I used to feel shy. I used to feel shy when we would, ah, I never used to come alone at first, I used to come with someone, maybe my aunt, mom, my elder sister, my elder brother, yeah, one of them I'd bring (Chai, F/18)*

> *My mom would mostly accompany me, she would sacrifice her work or my sister, in the first place she knew that if she says I should come alone I would never come here. I would probably do something else. So she would just use psychology and say, ah since today it’s your appointment day so you will go with your sister so that she should also buy for you food. And she would also make excuses, the roads and everything else. By then I knew how to cross the road,* so just a *way for my sister and her to accompany me (Dexter, M/19)*

However, this dynamic of dependence shifts over time as participants describe increasing involvement in their HIV treatment and care as they got accustomed. They describe their increased ability to engage in self-care behaviors and reduced reliance on caregivers and family for treatment-related support. This included keeping track of their own clinic appointments and attending them on their own.

> *I used to come with my aunt that, she’s the one who has been bringing me here. Since I was 14, yes from 14 then she stopped then I started coming alone because I knew all the procedures by that time cause in the beginning I didn’t know anything, like the procedures, where you have to start, where you have to get your drugs, answering the doctor like all those stuffs, I never knew anything, so my aunt was a guide in that procedure (Felix, M/19)*

> *…so used to feel so shy when the doctor is asking me questions, so he never used to ask mom or my elder brother or whatever, but she used to ask me directly, saying, I want Chai to answer me, yes. So I used to chat, we talk we talk, and ah that’s how I, I even got used, now I do come alone. If I want, the way I’ve come just today, I just came to learn there, just said, ah let me just go and learn something to help me then I go to school, just like that (Chai, F/18)*

> *They [mom and sister] accompanied me but there was just a time where everything had changed, ah social, I got used to the system and I felt I can come alone, and I was social with doctors and like that (Dexter, M/19)*

Participants described becoming self-reliant for their adherence through reminding themselves to take their medication and being responsible for storing their medication and not relying on caregivers or family for adherence support, e.g. medication reminders.

> *my cousins, each and every time they used to encourage me, or if I will forget like they would go in my room and get the bottle and give it to me, that its time take your medicine, so my cousins yes the main route for me to start taking my ARV's on time, each and every day. And up to now I'm taking alone (Felix, M/19)*

> *Right now I keep my medicine at home and I take it, yeah, no one reminds (Dexter, M/19)*

Over time participants describe adherence becoming a habit, something they are so used to doing they remember automatically.

> *Sometimes it's like if you have no time, it's like stuck in your head like, if you're used with something like each and every time like 19, 19 let me say 19, 19, 19 there will be that sensibility that you have like, there's something that I have to take around a certain time. Yeah, it will be like attached to you (Felix, M/19)*

> *…it clicks, I know even if I'm asleep, maybe Saturday Sunday I don't go to school, I'm asleep maybe I slept early, maybe by 19 but if it reaches just 20, I don't how it happens it just clicks since it's in my mind so I cannot sleep minus taking that (Chai, F/18)*

6.2.7 Peer pressure to engage in risky behaviors- *"Most of them indulge in unprotected sex"*

Engagement in risky behaviors is an issue of concern among adolescents, as adolescence is a time when individuals may begin to experiment and engage in behaviors that may be harmful to their health. Participants described experiencing peer pressure to engage in risky behaviors as a challenge that they have faced, highlighting emerging risks to the health and wellbeing of ALHIV during adolescence. They described drug use as common among their adolescent peers and the pressures they have experienced to engage in it.

> *…also on the same drug abuse there's what you call having 'Bluetooth', where you get drugs, you insert in blood and all that, then you use the same injection to insert the drug in other yeah, people's body. So I think the usage of drug is too high (Sitali, F/20).*
>
> *One thing I've noticed with adolescents is also drug abuse, cause when I was in Grade 8 I was almost a victim where I was just influenced, take up drugs cause you know I didn't want to be bullied and all those things. Everyone wants to feel how it is to be high, to enjoy life, they feel that's where the enjoyment is (Dexter, M/19)*

They also described peer engagement and the pressures they have felt to engage in risky sexual behaviors. Pressure to engage in unprotected sex was described by male participants.

> *Most of them indulge in unprotected sex, like they do know where to come and get the condoms from, they just don't feel like doing it. Others think like, no there's something no, I can withdraw whatever whatever (Charles, M/17)*
>
> *Peer pressure from friends whereby you are seeing others engaging in maybe unprotected sex, or who want to try it. Like it's a trend now, sex has become a trend, yeah, indulging in sexual activities, where they're too excited about life, cause this one's doing it, cause this one said sex is nice, someone says oh I want to try what's nice about it (Dexter, M/19)*

In the quote below Fumina describes the pressures she experienced from her boyfriend to consume alcohol, use drugs and engage in sexual activities.

…for him he was more of a wild person, he would tell me, 'oh babe let's go drinking', I'll be like, 'I don't drink I don't take alcohol', 'oh babe let's go smoke hashish', I'm like I don't smoke, so he was like, what do you do, I'm like I watch movies and read novels. So um, even after we passed through that a few months and he told me he would like to have sex with me, and I refused, like I strongly refused, it wasn't like that shy no, it was just like that no that comes from your stomach. You know like automatically your brain was set, it was programmed to say, you must say no to sex before marriage and what not (Fumina, F/19)

Female participants described engagement in transactional and intergenerational sex among their female peers and the pressure they have experienced to engage in such behaviors.

> *People are envious, when I say envious I mean like for us girls. I would see my friend my age is driving or she's got a very good phone, I'll be like oh okay I need that phone, okay I need that laptop, okay I need that gaming system, or something like that, and then, I inquire about it, they end up saying, no I got it from my boyfriend, and then when you see the boyfriend, it's like a 20 year gap, that's not even a boyfriend, that' supposed to be like your father or something, he's way too old (Fumina, F/19)*

> *Most of our friends would force us to do things like if we admire things, like if they have things we would admire them and then if we can't manage to get them our friends would force us in a wrong direction to say 'get a blesser, he would give you money', then you go out with them because you want something from them (Bianca, F/17)*

> *I see friends, they have big phones, then they tell me that they are getting these phones from men, and if I want to get that phone I should sleep with the men then I might get (Naka, F/19)*

6.2.8 Self-disclosure concerns and experiences -*" it's not very easy but now I've reached a point I can disclose"*

Similar to the previous theme, this theme highlights emergent issues faced by ALHIV as they navigate living with HIV. Participants described self-disclosure of their HIV status to others as a significant challenge due to the stigma associated with it. Participants described their experiences of disclosing their status to family, friends and romantic partners for various reasons.

Participants described disclosing their status to family and friends to receive emotional support.

> *I've got a good friend of mine, I've been growing up with him since childhood, so he's like a brother to me, I told him I'm positive, that's*

> *how he was like, ah you know even me I can't stop playing with you because you're positive, because you and me have come a long way and were still going. I 'm like at least I have someone whose there for me. When I need anything I'm always, I can count on him (Donald, M/16)*

> *When I told my best friend, my male best friend it made it easy for me, for us to communicate cause, there were times when I was low, and he'd be like, 'What's wrong? What's wrong?' and I was like, 'You don't want to know, you don't want to know'. And now that I told him he's there he supports me, he's like everything is ok, have you taken your medication, have you eaten, this this this (Bianca, F/17)*

Participants also disclosed their HIV status to family and friends to receive instrumental support.

> *I thought that if any problem happens to me, I can easily tell them, so that they should help me (Suwi, F/17)*

> *You might like, those people that have tendencies of forgetting, maybe your grandmas not in town, they're just alone then you forget maybe you sleep. You won't drink. So maybe like you tell your uncle, you tell this one, you tell this one so that when you sleep at least somebody wakes you up and says 'you have to drink your medicine' (Chisanga, M/17)*

> *I chose to tell my friend, like the way I come here, um, I'll go, from here I'll take my medicine, I'll just put in my bag then I'll go direct to school so, the person that I sit with yes, next to me, she's the one who knows, so in case I leave the classroom since I'm the class monitress, in case I leave the classroom, she'll take good care of my bag saying, there's something privacy, no one has to know, so she'll take good care of my bag, yes no one would touch it (Chai, F/18)*

Some participants described disclosing their HIV status to family members and friends whom they spent a lot of time with to facilitate their adherence. They expressed wanting to feel comfortable to take their medication around them to avoid disrupting their adherence.

> *I chose to disclose to my friend because, sometimes he would come over, he started working at a filling station, so he would come over, maybe he sleeps at my place, now all of those times he would come to sleep at my place it will be inconvenience because, I take my medication 21 hours and then, it will be like he's in the bedroom because, we just usually hang out in the bedroom, everyone else in the sitting room watching TV, and then I'll be like, I would always make up an excuse so, I just decided, no we've been friends for a long time let me tell him he'll understand (Chilando, M/19)*

> *With my family I knew maybe if I go for a holiday there, my cousins place where I used to go for a holiday it would be very hard for me to take adherence, you just know at someone's place where it's not your home where you can make your own rules. You find everyone maybe they're all in the bedroom, your cousins, they're all talking and your medicine is there, your time for taking medicine will be there, so rather than missing I had to talk to my cousins and it also helped me, gave me support where they would remind me to take my medicine (Dexter, M/19)*

A few participants described disclosing their status to friends and relatives in response to frequent questioning about their behaviors, including regular clinic visits and medication taking.

> *… she [friend] used to ask me, Chai why do you go to the hospital very often, every after 6 months I'm going to the hospital, I'm going to the hospital, and I used to lie to say, okay I've got the same problem of my hearing, so she was like, ah no okay it's not right, every time every time, so I just decided okay let me just disclose it since I trusted her, even now I trust her, that's how I disclosed (Chai, F/18)*

> *She [cousin] kept on asking and asking and asking, so just to kill her curiosity cause I knew she was going to start asking other people in my family who didn't know, and then there will be like some weird family meeting to know why is he doing this, is he a drug addict and stuff like that so I told her, and I knew she was very confidential so she was like, I won't tell anyone (Chisha, M/19)*

Some participants described the way they felt upon disclosure of their HIV status. Some described feeling immense relief after disclosing their HIV status to family and close friends.

> *I felt I was not the only one carrying that burden, I felt that burden was being shared among the family, it's not only you to carry it. Felt kind of more of a relief, that more people know (John, M/19)*

> *I used to feel out of place but when I told them I felt relieved. I just like told them and I was just like free (Ruby, F/19)*

> *I felt like I was carrying a burden, like it was a burden to me, at least when I disclosed to them, I felt relieved cause I never wanted to hide it from people I'm so close to, it's why I actually told them and it actually made me feel much better (Katie, F/19)*

Interest in romantic and sexual relationships emerge during adolescence and disclosure to partners becomes increasingly important. Very few participants described experiences of disclosure to romantic partners. A few disclosed their status because they felt they wanted to be accepted fully for who they were and to find out whether their relationships were worth investing in further.

> *I've disclosed to some girls, I've disclosed my status just for them to accept me for who I am, though it's not very easy but now I've reached a point I can disclose (Dexter, M/19)*

> *I didn't want to waste time for anyone, I wanted him to choose either to be with me or to let go of me, that's why I decided, I was like, what I'm going to tell you um, it's because I trust you and love you so it's now you to decide, me I'll just do my part by telling you, that's how I disclosed (Chai, F/18)*

Some described feeling morally obliged to do so as they believed it would be wrong to be in an intimate relationship with someone and not disclose their HIV status.

> *It wouldn't be cool like, you're dating them whilst you're holding back something, something that is of the most utmost importance to your life (Charles, M/19)*

> *Like it's not okay to be in a relationship with someone who doesn't even know your status, that's why I had to tell him (Elyse, F/17)*

> *I can't just stay quiet whereby I know, okay I'm not even at peace, I won't be at peace whereby, I know I'm dating but am not disclosing, I know because it's like a sin, I'm committing a sin. So I would rather tell her, whatever she'll take, if she wants to leave me she'll leave me but if she stays, she'll stay (Donald, M/16)*

Lastly, some participants disclosed their status to partners to facilitate safer relationships, e.g. safer sex.

> *I felt I needed to cause me having a boyfriend I have to tell him the way I am, in case he starts asking for stuff which I can't even give like, if he starts asking for sex and everything, so I told him (Tukiya, F/19)*

> *Then with the girls, you know I wanted to have a safe relationship where they would, they would accept me as I am and as well also, not just, you know there are just certain times where maybe she can become horny and everything else, wants to have sex. So at least she should have a conscious of protection, or anything. Anything can happen, Valentine's day, anything can happen, birthday, anything. So I just thought of protecting my partner (Dexter, M/19)*

However, participants also emphasized the precarious nature of disclosure to romantic partners. They described the difficulty involved with such decisions, highlighting the often fleeting nature of adolescent relationships and the fear of rejection.

> *I normally meet guys, I've got a boyfriend, so you find that maybe the guy that I met doesn't know anything about HIV, or if I have it doesn't even show, so it's so hard to start telling somebody to say, okay I'm like this like that cause its privacy, maybe in our journey it can, we can broke up, so it's so hard to disclose to someone (Chai, F/18)*

> *It's a little bit uncomfortable when you, you're in a relationship cause you would want to tell that person and maybe you'll think maybe that person won't like it and will just leave you just there and then, that's my experience. I would like to tell my boyfriend about my status so that I can be free and feel comfortable whenever I'm near him (Anna, F/19)*

> *I would like to tell people who are out of the family but, for you to tell someone you really have to trust that person, like you really really have to trust that person because most people you like tell them like for an example, you tell your girlfriend be like, no I got this and that and she'll be cool with it, one minute she's cool with it, the next minute you argue, the whole world knows, so you gotta be very cautious with who you tell (John, M/19)*

Participants emphasized that decisions to disclose their HIV status to others are not taken lightly. Some described the considerable amount of time and energy spent on disclosure decisions, including the recipients of disclosure. Participants reflect on various aspects including their relationship and the trustworthiness of the person.

> *I'm still looking for the perfect time and then, the right person cause I have to see someone who is willing to keep my secret, who is willing to understand me, and then if I find out that person then I'll be able to express myself. So I haven't find that in any of the people I stay with, and I still have to dig deep in there. I need to look for a right person and I'll see, I'll find out the right time (Julius, M/19)*

Participants also described gauging potential reactions of recipients of disclosure to help them with their disclosure decisions. This strategy involves testing individuals in their social networks in some way to try and avoid potential negative consequences of disclosure.

> *My home friends, school friends they don't know, cause I remember at some point like I started the story and like the way my friend answered… There was a club at school called Anti-AIDS Club, I told my friend that we should attend, she answered me like, those people who are HIV are the ones who attend that group. And I felt bad knowing that me I'm HIV positive and the person who I call my best*

> *friend, thinks that about people with HIV so like, I never told any friend (Tukiya, F/19)*

> *I tried to like, the topic we were learning at school about HIV positive, then I asked one of my friend, I was like 'What could you do if you found that you're HIV positive', and then she was like 'What? No I can't, why ask, if they found me HIV positive then I would kill myself ', I said that ah 'Do you know that some they can live a longer life than you', goes 'No that's a lie, I can't be found HIV positive'. So, I just saw my best friend's reaction, I was like no this one I can't tell her that am HIV positive (Mindy, F/18)*

> *As for me I've disclosed to my best friends, that's a guy and a girl, and some church members, those are my friends. As for now there's nothing that I've heard so far they just took it as its normal because they know that I do teach about this and before I did educate them about the same HIV thing, I did talk to them, I told them how would you feel if you'd find someone in your family or your friend would be in this kind of state, I'll first hear their opinion, what they answered, then what they gave out, I was like okay then, I'm HIV positive how would you take it, was like, 'woah we didn't know', that's how they took it, they just went 'woah' up to date, we laughed proper, everything, we do things normally, it's just a normal life (Felix, M/19)*

6.3 Discussion

The findings from this study demonstrate various experiences, events, transitions, and challenges that occur over the life course of a young person living with HIV. Many participants experienced acute or repeated bouts of severe illness in childhood which eventually led to their HIV diagnosis. Similar experiences of prolonged illness before the discovery of HIV status were identified in other studies among ALHIV (Denison et al., 2015, Dorrell and Katz, 2013, Pienaar and Visser, 2012). These findings highlight the importance of HIV testing, e.g. provider initiated HIV testing, as some participants described being in and out of clinics for a variety of reasons for quite some time before their HIV status was discovered and suffered significant consequences as a result, including poor quality of life, as ALHIV describe limited capacity to engage in daily life activities, including going to school. Experiences of prolonged illness in childhood and early adolescence were also found to facilitate treatment engagement, particularly adherence to treatment in this sample. Similar findings of treatment confidence as a motivator for engagement in treatment have been described in other studies among adolescents (Mutumba et al., 2015a, Denison et al., 2015, Petersen et al., 2010).

Discovery of HIV status was a significant life event for all participants that occurred suddenly, with many having described feelings of shock and/or surprise. The experience was a turning point that forever changed the lives of participants (Hutchison, 2011). Other studies have also described HIV diagnosis as a turning point in the life course (Tsevat et al., 2009, Bruton et al., 2018, Wekesa and Coast, 2013). This turning point in the lives of participants generally occurred during early adolescence as the sample's average age of disclosure is 12 years old. As discussed in the previous chapter, disclosure of HIV status was a disruptive event in the lives of participants with significant emotional and psychological consequences. Participants stressed how finding out their status changed their lives as they knew it and as they thought it would be. As a result of these changes in perceptions, findings demonstrate that participants had to take up new behaviors and change or stop partaking in routine behaviors and/or activities as a result of their HIV status.

Findings show that participants experienced changes in their perceptions and expectations concerning living with HIV. Participants described shifting from feelings of doubt concerning their futures (e.g. fears of experiencing early death) to feeling more optimistic about their future and life plans (e.g. career and family). This seems to occur after a period of adjustment suggesting an accommodation and acclimatization to navigating life with HIV. Other studies among adults living with HIV have also found changes in improved outlook on life (Tsevat et al., 2009, Psaros et al., 2015, Courtenay et al., 2000, Kremer et al., 2009). In discussions concerning shifts in perspectives, older adolescents suggest that the amount of time knowingly and unknowingly living with HIV influenced these shifts. This may be a result of the fact that on average older participants in this sample may have had more time to come to terms with their HIV status having been aware of it longer. This suggests that the passage of time since disclosure of HIV status can significantly influence adjustment. Few studies have explored the experiences of PLWH over time (Psaros et al., 2015), however passage of time since HIV diagnosis has been found to be associated with changes in perspectives leading to gradual acceptance and adjustment among adults (Psaros et al., 2015, Courtenay et al., 2000).

Zambia is a middle-income country with a high unemployment rate (15% in 2008) and widespread rural poverty (Central Intelligence Agency, 2022). Poverty is a significant contextual factor underlying the challenges faced by many young people in Zambia. A Multidimensional Overlapping Deprivation Analysis found that children aged 0-17 in Zambia are monetarily poor and face overlapping forms of deprivations, including health, nutrition, sanitation, water, information, child protection, education and housing (Ministry of National Development Planning, 2018), indicating that many low-income households are struggling and unable to afford basic necessities. A few participants of low-socioeconomic status described not being able to complete their education because they were unable to get financial support to cover their school fees and other associated costs. Most of these dropped out of school after completing primary and/or during secondary. A minority reported not completing basic primary education (until Grade 7) which is tuition free. Most of the participants that reported dropping out of school were orphaned and resided with extended family. Orphaned children are at greater risk of not completing their education than their non-orphaned peers due to various reasons including the inability to pay tuition fees, needing to care for sick parents and/or younger siblings and the need to assist with household chores (Zambia Statistics Agency et al., 2019). As a result, these participants are at increased risk of experiencing negative outcomes, including poorer health in adulthood compared to their more educated peers (Ross and Wu, 1995, Zajacova and Lawrence, 2018, Raghupathi and Raghupathi, 2020).

Apart from experiencing transportation challenges as a result of low socioeconomic status, none of the participants in this study described experiences of insufficient food, inadequate shelter and the lack of other basic necessities. Numerus studies demonstrate that adults from disadvantaged childhood backgrounds experience poorer health outcomes than their peers from less disadvantaged backgrounds (Poulton et al., 2002, Keetile et al., 2021, Puolakka et al., 2018, Conroy et al., 2010). For example, a study by Keetile et al. (2021) in Botswana found that poor socioeconomic status in childhood was associated with smoking, alcohol consumption, poor fruit and vegetable consumption, obesity and hypertension. The literature suggests that the life trajectories of individuals who grew up in disadvantaged homes may significantly differ from those who did not. Therefore, it is crucial that support is provided to ALHIV from low socioeconomic backgrounds to protect them from the potential adverse effects of their disadvantaged backgrounds in later life (Poulton et al., 2002).

Participants also described experiencing HIV-related stigma within the home and school context (Kimera et al., 2020a, Mutumba et al., 2015a, Pantelic et al., 2020). Within the home they experienced enacted stigma including being given their own utensils, clothes and having to sleep in isolation. Studies by Mutumba et al. (2015a) and Kimera et al. (2020a) in Uganda similarly found that adolescents and youth predominately experienced stigma in the home and school contexts. Kimera et al. (2020) also found that participants that were orphans had reduced capacity to challenge the way they were treated. This resonates with the findings from this study as the enactors of stigma within the home were not biological parents but were either step-mothers and/or aunts that were caring for double orphaned participants or single orphans whose parents were unable to care for them at the times when these experiences occurred. These findings are in contrast to the findings described in the previous chapter that ALHIV were given special treatment, suggesting that ALHIV are more likely to experience discriminatory treatment as a result of their HIV status in homes where their main caregiver is not their biological parents, contributing to the limited literature on how family structure influences the psychosocial wellbeing of ALHIV (Wowolo et al., 2022).

Parental loss is a traumatic, painful and disruptive life event, especially during childhood (Tafa et al., 2018, Debiasi et al., 2021). A number of participants in the sample were single or double orphans. The loss of their parents was described as having impacted their access to education and their experiences of stigma. Participants emphasized the practical and/or immediate consequences of losing their parents and coping with the difficulties of life by focusing on their needs and livelihoods, which has been highlighted in the literature on the agency and resilience of vulnerable and orphaned children affected by HIV/AIDS (Chase et al., 2006, Skovdal and Campbell, 2010, Skovdal et al., 2009). The death of a parent is associated with poor health and psychosocial outcomes across the life course, including during adolescence and adulthood (Osterweis et al., 1984, Umberson and Chen, 1994, Luecken, 2008, Debiasi et al., 2021, Feigelman et al., 2017). For example, Umberson and Chen (1994) found that adults who had experienced childhood bereavement experienced increased psychological distress, alcohol consumption and declining physical health. And among children living with HIV and/or AIDS-orphaned children, parental death is associated with poor psychological wellbeing (Chi and Li, 2013, Nabunya and Ssewamala, 2014, Cluver and Gardner, 2006, Atwine et al., 2005).

Within the school context participants experienced stigmatizing behaviors from their teachers and peers (Mutumba et al., 2015a, Martin et al., 2022). These experiences contributed to the internalization of stigma experienced by participants and compounded the internalized stigma experienced by some post-disclosure of their HIV status as described in the previous chapter. These experiences of stigma negatively affected the psychological wellbeing of participants, highlighting the need to address stigma within the home and school contexts.

Illness management is crucial, especially for chronic conditions like HIV that require lifelong engagement with treatment. Self-management of illness is a key transition in the life course of ALHIV, and has important implications for their health and wellbeing. Findings show that over time ALHIV gradually take on more responsibility and management of their illness and grow increasingly less dependent on caregivers (Blum et al., 1993, Lanyon et al., 2020). Participant narratives demonstrate dependence on caregivers, particularly when they initially began treatment and then describe a shift to taking on greater responsibility. This may be explained by increasing autonomy, capacities for independent thinking, decision-making and self-reliance (Salmela-Aro, 2011, McNeely and Blanchard, 2010) as adolescents mature. The role of caregivers in treatment engagement may be especially crucial during early adolescence as younger adolescents tend to be more reliant on their family for support. Similar findings of ALHIV assuming greater responsibility for treatment have been reported in other studies (Denison et al., 2015, Lanyon et al., 2020). The time spent on treatment and engaging in treatment related behaviors may also play a role in facilitating the self-management of illness, as participants highlight becoming used to adhering to their medication and going to the clinic for appointments. The ability of ALHIV, especially older adolescents on the verge of transitioning to adult care to self-manage their illness has significant implications for their treatment and wellbeing, especially since various barriers to successful transition to adult care in resource limited settings have been identified (Danhoundo et al., 2018, Jones et al., 2019a).

As described in the previous chapter, adolescence is a period in which individuals may begin to experiment and engage in risky behaviors (Gore et al., 2011). Engagement in such behaviors tends to peak in middle adolescence, and includes alcohol use, drug use and sexual-risk taking (Salmela-Aro, 2011, Balocchini and Chiamenti, 2013, Gore et al., 2011). Findings show that during the life course, engagement in risky behaviors and the pressure to engage in such behaviors is a significant challenge faced by participants.

Peer pressure was described as a significant influence on the behaviors of participants and their peers, including the pressure to consume drugs and engage in risky sexual behaviors. Studies among adolescents have found that peer norms influence the attitudes and behaviors of adolescents regarding engagement in risky behaviors as adolescents are concerned with fitting in (Potard et al., 2008, Lundborg, 2006, Prinstein et al., 2001). Other studies among ALHIV have reported substance use (Nyongesa et al., 2021, Alperen et al., 2014, Brittain et al., 2019, MacDonell et al., 2013) and engagement in risky sexual behaviors (Elkington et al., 2015, Koenig et al., 2010, Ssewanyana et al., 2018b, Gavin et al., 2006, Zgambo et al., 2018, Mengwai et al., 2020), e.g. multiple sexual partners, unprotected sex, transactional sex, etc. and highlight the importance of comprehensive education concerning risky behaviors in this population due to the potential negative implications for their health and wellbeing.

Transactional sex occurs in the context of high rates of poverty and widespread disadvantage (Zamudio-Haas et al., 2021). None of the participants described engaging in transactional sex but it was described as occurring among their peers. Other studies in SSA have found that adolescent girls and young women (AGYW) engage in transactional sex for a variety of reasons, including to acquire desired items (Wamoyi et al., 2019, Duby et al., 2021). For example, Duby et al. (2021) found that AGYW engage in transactional sex to acquire luxury goods they normally do not have access to, including clothing and food. AGYW are under strong peer pressure to engage in transactional sex, especially those from disadvantaged homes. However, transactional sex increases risks of HIV (including re-infection) and other STIs and adolescent pregnancy (Austrian et al., 2019, Zamudio-Haas et al., 2021, Kilburn et al., 2018), highlighting the importance of addressing the SRH needs of adolescents.

The pressure to engage and/or engagement in risky behaviors were largely described by older participants. This may be a result of their age, as they may have had more opportunity to be pressured into and engage in such behaviors which tend to peak during middle adolescence.

Findings indicate that over the life course certain aspects of living with HIV become more salient, including self-disclosure of HIV status. Findings concerning the self-disclosure experiences of participants suggest that the need to disclose one’s status to others may arise in various contexts and for various reasons and that the motivations can be both self and other focused. Findings also show that motivation for disclosure differed depending on the type of relationship with the recipient of disclosure (Ssali et al., 2010). Participants disclosed their status to family and close friends to receive emotional and instrumental support with similar findings reported in other studies among ALHIV (Mutumba et al., 2015a, Petersen et al., 2010, Midtbø et al., 2012). As highlighted in the previous chapter, social support significantly improves psychosocial outcomes and helps ALHIV manage some of the difficulties they face, e.g. coming to terms with their status and adherence to ART. Participants in this study also described disclosing their status to relatives and friends due to frequent questioning, which for most was a result of changes in behavior and not changes in appearance in contrast to other studies (Ssali et al., 2010).

Additionally, participants described experiences of self-disclosure to romantic partners, highlighting the increasing importance of serious intimate relationships during adolescence (Salmela-Aro, 2011, McNeely and Blanchard, 2010). During adolescence, individuals begin developing their sexual identity and as their interest in romantic and/or sexual relationships increase, may begin engaging in sexual behavior, e.g. experimentation, romantic friendships and dating (McNeely and Blanchard, 2010). Disclosure to romantic and/or sexual partners has implications for the control of the HIV epidemic. Findings described various motivations for disclosure to romantic partners, including moral obligation, acceptance and to facilitate safe relationships with similar findings reported in adolescent and youth studies (Mengwai et al., 2020, Mlilo et al., 2020). However, these experiences were heavily described by older participants which may be a result of older participants having had more opportunity to engage in such relationships and experience with disclosing their HIV status to their partners. Other studies among adolescents and young adults living with HIV have found increased age and increased length of time since diagnosis of HIV status to be associated with disclosure of HIV status to sexual partners (Weintraub et al., 2017, Batterham et al., 2005). Findings also suggest that disclosure to sexual partners is associated with safer sex among ALHIV, contradicting findings from other studies in the literature (Toska et al., 2015, Dempsey et al., 2012). However, more studies need to explore this important area of concern.

Similar to the findings concerning self-disclosure described earlier in this thesis (Chapter 3), low rates of disclosure were reported across study participants including to romantic partners, similar barriers to self-disclosure (e.g. fear of stigma and discrimination, including rejection from friends and partners; ridicule; onward disclosure of HIV status and being told to not disclose their status by caregivers) and only a few participants disclosed their HIV status to certain individuals for specific reasons (e.g. gain emotional and treatment-related support). Regarding facilitators of disclosure, trust was reported in the findings of both chapters as an important factor. Lastly, negative consequences of non-disclosure on medication adherence were also emphasized by participants. However, unlike the findings from the review, the findings from the adolescent study suggest a potential link between disclosure and intention to engage in safe sexual behaviors.

Findings from this analysis also shed light on how ALHIV may prepare for self-disclosure including consideration of the traits of an individual e.g. trustworthiness, closeness, etc. and gauging potential reactions by indirectly seeking information on their attitudes towards PLWH, with similar findings reported in adolescent (Madiba and Mokgatle, 2016, Greenhalgh et al., 2016, Siu et al., 2012) and adult studies (Bilardi et al., 2019). A study by Greenhalgh et al. (2016) similarly found that young adults disclose early before becoming too involved in their relationships and test partners for likely reactions to their disclosure. However, unlike my findings they also identified the use of condoms as a means of avoiding disclosure to sexual partners (Greenhalgh et al., 2016). Disclosure of HIV status is a significant challenge faced by PLWH (Chaudoir et al., 2011) due to fears of stigma and discrimination, placing ALHIV in a unique situation as they try to navigate living with HIV and their relationships with their peers. However, findings demonstrate that adolescents struggle to balance disclosing their HIV status with their fears of potential rejection from their partners, with similar findings concerning hesitancy to disclose HIV status to romantic partners reported in other adolescent studies (Zamudio-Haas et al., 2012, Toska et al., 2015, Mutumba et al., 2015a, Madiba and Mokgatle, 2016, Mengwai et al., 2020).

Participant narratives demonstrate that disclosure of HIV status was not easy but suggest that the perceived need to disclose one's HIV status may become increasingly relevant and/or necessary to receive social support, enhance their adherence and protect themselves and their partners, underlining the importance of supporting ALHIV with the disclosure process. The findings of this study contribute to the limited literature examining the self-disclosure experiences of ALHIV, particularly addressing gaps related to facilitators and motivation to disclose that were identified earlier in this thesis (Chapter 1 and Chapter 3).

An important limitation of this study is that the decision to apply a life course approach was decided post-hoc and the nature of the findings are limited by its cross-sectional nature (See 8.3). However, the findings of this chapter contribute to the limited literature on the experiences of PLWH over time (Psaros et al., 2015) and particularly the application of a life course approach to examine the experiences of ALHIV. The findings highlight important events, experiences and challenges that significantly influence the wellbeing of ALHIV across the life course, highlighting unique challenges including engagement in risky behaviors, self-management of illness and navigating sexual and romantic relationships.

Conclusion

The findings of this chapter highlight important shifts, experiences and challenges faced by ALHIV across the life course, indicating important areas for intervention to support young people living with HIV as they age across adolescence and into early adulthood. The findings emphasize unique experiences of concern for the treatment of adolescents including engagement in risky behaviors, self-management of illness, and disclosure of HIV status which have a number of implications for engagement in HIV care and treatment. It is important that the unique experiences and challenges associated with adolescence are taken into account in the development of interventions to better support and enhance protective factors for young people across the life course as the experiences described here may differ and resonate differently among individuals in different life stages.

Chapter 7 “Our hands are tied”: Health Service Provider perspectives on the experiences of ALHIV

7.1 Introduction

This chapter describes the perceptions of Health Service Providers (HSPs) on the experiences of ALHIV with engagement in care along the HIV care continuum. In the context of this study HSPs are defined as individuals involved in the provision of HIV-related curative and preventive services to ALHIV, in both clinical e.g. health facilities and community e.g. NGO settings. As discussed earlier in this thesis (Chapter 1), NGOs play a significant role in the delivery of HIV/AIDS treatment and care services in Zambia, and were described as a significant source of social support in the findings on the experiences of ALHIV (Chapter 5).

HSPs play a significant role in the treatment of health service users or clients and their understandings of client needs and experiences can significantly affect client health experiences and outcomes (Cerier et al., 2018, Stewart, 1995, Kelley et al., 2014, Wei et al., 2017). Studies examining health care provider-client relations have revealed that differing priorities between both parties (Kennedy et al., 2017, Voigt et al., 2010, Fredericksen et al., 2019, Brundisini et al., 2015) affect health outcomes (Starfield et al., 1981) and quality of care (Lesho et al., 2009, Andén et al., 2010, Voigt et al., 2010, Thomson and Doody, 2010), demonstrating that health care providers often have limited understandings of client experiences and the need to examine their perceptions. The quality of relationships is also important as studies examining relations between health care providers and clients living with HIV found that positive health care provider-client relationships are associated with increased social support (George et al., 2009, Kumar et al., 2015, Cummings et al., 2014), adherence (Roberts, 2002, Chirambo et al., 2019, Beach et al., 2006, Ankrah et al., 2016, Croome et al., 2017) and engagement and retention in care (Mwamba et al., 2018, Mallinson et al., 2007, Flickinger et al., 2013, Yehia et al., 2015).

This chapter builds upon the findings from the previous chapters by examining the perceptions of HSPs on the experiences and challenges faced by ALHIV across the HIV care continuum. As significant players in the provision of HIV treatment and care services, they are very knowledgeable of client experiences and familiar with the health delivery system. They are also well placed to highlight factors undermining achievement of universal HIV/AIDS treatment targets, including the UNAIDS goal to end the AIDS epidemic by 2030. Despite studies exploring HSP understandings of the treatment and care experiences of PLWH (Bogart et al., 2013, Coetzee et al., 2011, Loeliger et al., 2016, Taylor et al., 2018, Nhassengo et al., 2018, Moucheraud et al., 2019, Vyankandondera et al., 2013), there is a paucity of studies examining the understandings of HSPs in relation to young people living with HIV in resource limited settings, e.g. adolescents. This study seeks to address this gap in the literature, as it is important to examine HSP perceptions of the experiences, barriers, facilitators and needs of ALHIV in order to improve engagement and retention in HIV care and treatment (Gelaude et al., 2017). The research questions framing this analysis are: *What are the perceptions of HSPs on the experiences and challenges faced by ALHIV? What issues or challenges do they face in working with adolescents? What are their perceptions of what can/should be done to better support ALHIV?* The findings from this chapter will be triangulated with those from the adolescent chapters.

Table 7-1: Health service provider participant characteristics

	Participant Pseudonyms (sex)	Role	Setting	Services targeting adolescents
1	Felicity (F)	Nurse	Clinic	HIV treatment and prevention
2	Chanju (F)	Adolescent Counselor	Clinic	Counseling and support
3	Chikondi (F)	Nurse	Clinic	HIV treatment and prevention
4	Tiwonge (F)	Nurse	Clinic	HIV treatment and prevention
5	Nthudza (M)	Adolescent Counselor	Clinic	Counseling and support
6	Thando (M)	Social worker/Counselor	Clinic	HIV-related community outreach activities; counseling and prevention
7	Kangwa (F)	Doctor	Clinic	Treatment and prevention
8	Benson (M)	Clinician	Clinic	Treatment and prevention
9	Salome (F)	Adherence support worker/Adolescent Counselor	Clinic	Counseling and support
10	Eniya (F)*	Country Director	Community	HIV-related community prevention outreach activities; nutritional support; treatment and prevention services and palliative care targeting vulnerable children, adolescents and pregnant women
11	Matt (M)*	Deputy Director of Programmes and Operations	Community	HIV-related community prevention outreach activities; nutritional support; treatment and prevention services and palliative care targeting vulnerable children, adolescents and pregnant women
12	Chibulu (F)*	Program Coordinator	Community	HIV-related community outreach activities; recreational, educational and income generating activities; clinical support programming and

				counseling and prevention services for adolescent girls
13	Lilian (F)*	Program Coordinator	Community	HIV-related community outreach activities; recreational, educational and income generating activities; clinical support programming and counseling and prevention services for adolescent girls
14	Lazarus (M)	Senior Technical Officer	Community	HIV-related community prevention outreach activities and clinical support programming
15	Beatrice (F)	Communications and Advocacy Officer	Community	Advocacy work; community outreach prevention activities and treatment related support through implementing partners
16	Chibeka (F)	Senior Program Manager	Community	School and community-based HIV prevention programs; recreational activities and provides SRH services for adolescent girls
17	Vincent (M)	Program Officer	Community	HIV and SRH sensitization programs in communities and health facilities and advocacy work
18	Kalolo (M)	Project Coordinator	Community	Runs support groups and trains peer educators; provides education grants; capacity building activities and promotes adolescent participation in policymaking
19	Alfred (M)	Program Coordinator	Community	Community and school-based HIV prevention activities; organizes support groups and trains peer educators

*Eniya and Matt; and Chibulu and Lilian work for the same organization and were interviewed together

7.2 Results

The analysis identified two global themes about the perceptions and experiences of HSPs who work with ALHIV. These themes reflect HSP understandings of the challenges faced by ALHIV with treatment engagement and accessing health services, the difficulties experienced by HSPs with service provision to adolescents and what can be done to better support and promote the wellbeing of ALHIV.

7.2.1 Navigating adolescent health: the influence of diverse and dynamic personal and environmental factors

The individual personal experiences of individuals as well as their social environments significantly affect their health and wellbeing. Throughout the interviews participants emphasized the impact of the personal beliefs and experiences of adolescents and their surroundings on their wellbeing. The social environment in which an individual lives encompasses their “immediate physical surroundings, social relationships, and cultural milieus” (Casper, 2001, p. 465). This theme applies a socio-ecological lens to identify and contextualize the personal and environmental factors affecting engagement with treatment, service utilization and the wellbeing of ALHIV. This theme will be presented according to five organizing themes corresponding to the different levels of influence: individual experiences; personal relationships; health care system; community context and public policy (Table 7-2).

Table 7-2: Navigating adolescent health: the influence of diverse and dynamic personal and environmental factors

Global theme	*Organizing themes*	*Basic themes*
Navigating adolescent health: the influence of diverse and dynamic personal and environmental factors	Individual experiences	• Size of ARVs • Side effects • Pill burden • Treatment fatigue • Non-acceptance of HIV status • Feeling different from others • Fears of early death • Lack of information about treatment • Improvements in health • Engagement in activities
	Personal relationships	• Lack of/poor disclosure • Caregivers block access to health services • Lack of social support • Peer pressure to enagage in risky behaviors
	Health care system	• Distance to health facilities • Inconvenient clinic hours • Staff shortages

	• Health care provider attitudes • Lack of AFHS
Community context	• Poverty • Social and cultural norms • Faith and traditional healing • HIV-related stigma
Public policy	• Availability of third-line ARVs • External funding of ARVs • SRH policies

Individual experiences- *“they stop taking the medication during exams or crucial time”*

Individual experiences refer to the influence of beliefs, attitudes, personal experiences, knowledge and behaviors on the wellbeing of ALHIV. Participants described negative experiences with taking ARVs as barriers to adherence. They described difficulties adolescents faced with swallowing their medication due to their size:

> *…three quarters of them will say the medicine is big, its bitter. Yeah, because most of them complain they’re big I can’t manage to swallow it (Nthudza, Adolescent Counselor)*

They also described the experience of side effects as a barrier to adherence. These include nausea, dizziness and rashes which often deter adolescents from adhering to their medication.

> *Then others they'll tell you about side effects because these ARVs have got a range of side effects. Let's take for instance someone whose taking TLE (efavirenz/ lamivudine/ tenofovir disoproxil fumarate), which will bring about drowsiness, especially when they are just starting their treatment. I've seen situations where they stop taking the medication during exams or crucial time, they stop taking their medication because they just can't withstand the drowsiness, they want to stay awake and study and perform well at school. Others will say it doesn't taste well, you have some medicines that are bitter (Kangwa, Doctor)*

Adolescents are often in school and as reflected in the above quote, educational activities can affect their adherence. This suggests that ALHIV may struggle more with adherence at certain times or during certain periods of their lives.

Individuals taking medication for chronic illnesses may begin to feel overwhelmed or burdened by the amount or dosing schedules of their medication. This experience of pill burden which can affect willingness to adhere, was described by participants as another barrier to adherence. Participants described the taking of multiple pills a day and at various times as contributing to non-adherence among adolescents, especially those attending school.

> *Then for others it's the pill burden, especially if they cannot be put on the Atripla which is a one dose drug, you have to start with the other combination which may require them taking three tablets in the morning, another three tablets in the evening so that poses a challenge and they always ask as to why they cannot take the other drug as others are taking one single drug (Benson, Clinician)*

Similarly, treatment fatigue is another challenge faced by individuals taking medication for chronic illnesses. ALHIV were described as getting tired of taking medication every day and regularly engaging with treatment services.

> *…some of them will just come up with their own ideas to say, they're just tired to take drugs. Those are some of the challenges, just the adherence fatigue, they just get tired. They just get tired to take drugs, they'll just stop (Chikondi, Nurse)*

> *They just decide to stop, maybe they are tired of coming here every 3 months or every 6 months, they are just tired, they just drop out (Nthudza, Adolescent Counselor)*

Non-acceptance of HIV status was described as a barrier to adherence, as it affected the willingness of adolescents to initiate and adhere to treatment.

> *Most adolescents, it's not very easy for them to start treatment. So like those are the people that give you like pressure, cause you need to make sure that the client starts to take their medication. So it's challenging because of their acceptance, it's not very easy for the adolescents to accept (Salome, Adherence support worker/Adolescent Counselor)*

Participants described ALHIV feeling different from others who were not living with HIV as a challenge to adherence. These feelings of difference negatively affected adherence, as seeing family and friends not taking medication affected their motivation to adhere.

> *…maybe in that house they're the only ones that are taking that medication and no one else is taking, so they feel different from the others, they feel they are not normal adolescents, and sometimes that's what even leads to them stopping medication because they want to fit in, they want to feel normal just like any other adolescent whose not taking medication (Kangwa, Doctor)*

Adolescence is a period where individuals are concerned about their peer relationships and want to fit in. As reflected in the quote above, this suggests that for some adolescents the feeling or need to fit in may be more important than adhering to their medication. Participants also described adolescent fears of not fulfilling their goals/dreams as a result of their HIV status, as they feared dying early.

> *So young people do need a lot of psycho-social support. They are at the point where they're thinking, oh I want to be an engineer, is this the end of my dream as an engineer? Does it matter if I work hard in class or not, after all I'm HIV positive I'm dying any minute. So you really need to sit down with them and explain, you can live for a very very long life but, you need to take care of yourself, and this is how you need to take care of yourself (Eniya, Country Director)*

Lack of information and understanding concerning HIV treatment was described as a barrier to adherence. Participants described experiences of adolescents not adhering to their medication because they did not understand why they had to take it and experiences of unexpected side effects that they were not informed about.

> *…some it's also lack of information because, if you go there you just tell them these are ARVs, so what, I think they need more information to say, oh if you take these ARVs this is what it will do to your body and this is what will happen, but you just give someone to say you'll be taking these for the rest of your life, but you need to give them proper information so that they are aware if they stop, this will happen, so you give them both advantage as well as the disadvantage part of taking their medication. So most of them you'll find they'll stop cause they don't have information (Kalolo, Project Coordinator)*

> *…this is an adolescent, as soon as they get diarrhea they will stop and they lack one-on-one counselling where you really have to make me understand to say, you'll have diarrhea for a few days but it's normal. So it's about them not understanding the treatment regimen, and not understanding the drugs they're taking, how it's changing their body, the side effects that come with them (Chibulu, Program Coordinator)*

Some participants described perceived improvements in health as a barrier to adherence with adolescents noticing positive changes in their health deterring them from maintaining their adherence.

> *They have been adhering to treatment from childhood or from birth, they've been on treatment from birth and if for example a girl is 15, they will ask themselves they've been taking medicine for this long,*

> *I'm just fine, I'm not sick I'm healthy, so at times they don't want to adhere because they feel they are healed, they have been treated, to some extent they feel, I mean, what's the point of taking medication when I feel fine. So the fact that they are in good health because of them adhering for longer period their health is okay, so they tend to forget about medicines. I think that's the more reason why we have seen poor adherence among adolescents (Vincent, Program Officer)*

Leisure activities, e.g. engaging in social activities away from home when time for medication, was described as affecting adolescent adherence.

> *…for somebody like a youth, too many activities and experiments. They will be so active, they're so active in terms of, uh, works, so you'd find that they forget to take their medicine on time. You'd find that they have gone for a party, they forgot the medicine, they have gone for a trip, they have forgotten the medicine. So it's kind of hard to keep them on track, in making sure that they take their medicine at right time (Chanju, Adolescent Counselor)*

> *…when you know they go out, they have a specific time [they're] supposed to take their medication, most of them they leave their medication at home. Imagine you're supposed to take at 19 and then you go home at 02, the drug, so you won't take medication (Alfred, Program Coordinator)*

The individual experiences theme highlights the influence of attitudes, beliefs, personal experiences and behaviors on the health and wellbeing of ALHIV, especially with adherence to treatment. Participants described a number of factors that were of considerable importance in adherence to treatment. These ranged from the physical size of ARVs to engagement in social activities that contribute to medication non-compliance.

Personal relationships- *"so many of them failing on treatment because their parents are shielding them"*

Personal relationships refer to interactions with individuals within the social network of ALHIV and social support, e.g. relationships with family and peers and how they affect treatment engagement. Caregivers play an important role in the lives of adolescents and their behaviors have significant implications for the health of their children. Participants described the various ways caregivers affect the treatment experiences of ALHIV. Caregivers often have the responsibility of disclosing their child's HIV status to them and participants described lack of or poor disclosure of HIV status to adolescents as a challenge to engagement with HIV treatment. They cited caregivers withholding their child's status or misleading them over the reasons for their medication as affecting motivation or willingness to adhere.

> *First challenges that I've seen, which I can rate as number one, if an adolescent has not been properly disclosed to. There are certain adolescent whose parents are no more and they've been staying with aunties, grandmothers and all that, and the disclosure, you know they try to hide from them, they try not to tell them about the condition itself, until maybe they're grown up. So, if the disclosure is not done properly, they tend not to adhere well to treatment, they'll be on and off treatment (Tiwonge, Nurse)*

They described experiences of negative reactions to treatment among adolescents when they discover their HIV status on their own, including poor retention in care.

> *…we do not have the right to disclose, we wait for their parents to disclose, and if they do not disclose this child, as soon as they know that they're taking ARVs and the parents did not disclose, they stop taking their drugs. HIV is stigmatized, the only thing that they know is you got it through sleeping with somebody who had it. So if the family or the parents did not disclose and depending on how they're handling it, they will drop out of care (Chibulu, Program Coordinator)*

> *…those that, um, the parents disclosed to, you know, seem to do better than the ones who discover on their own. Because, um, my feeling is, those who, at least had bits of information, and when they discovered the parents were there to talk to them about it, I think that they usually, uh, turn out better than the ones that just discover on their own, because it becomes very serious, suddenly you don't just see this girl or this boy who was very dedicated, you know, they came for their clinical follow-ups, they came for their labs, they came for*

> *their medication, and suddenly they're not coming (Lazarus, Senior Technical Officer)*

The impact of poorly managed disclosure on the psychological wellbeing of ALHIV was discussed. Participants acknowledged its effect on the developing self-concepts of adolescents and emphasized the need to support caregivers with the disclosure process.

> *…I think it all starts with the issue of disclosure, from my experiences how have they found out. Um, because some of the girls come to the program for example, and they're saying, sometimes a friend whose like, I recognize that medication, so already mentally you find that some of them are traumatized because they've been taking medication and they're just being told it's for headache or something and they're not really mention. So that's something we've been working very closely with parents so that we're seeing a change in that because we're seeing that those are the issues that stick to these girls' minds (Chibeka, Senior Program Manager)*

> *Very often adolescents find out they're living with HIV later in life and I understand how at a time of establishing your own identity, trying to understand who you are, exploring sexuality, um, and that is all part of a process to establish people's identity. If within the process, you break it and say, you've been living with a condition that is not treatable and so it may lead you to death your whole life if you leave it untreated, it's something that is really unsettling, and this is something that I don't think enough work has been done in supporting the parents in telling their children about it. So a lot of children are finding out when they're adolescents, they've been taking a pill all their life, they google what the pill is, they found out it's ARVs and it happens in a lot of cases (Beatrice, Communications and Advocacy Officer)*

Caregiver denial of adolescent access to treatment services was described as a barrier to engagement with treatment. Caregivers were described as experiencing difficulties with coming to terms with their child's HIV status and preventing adolescents from initiating and adhering to treatment, which can lead to poor health outcomes. Preventing access to health facilities may also affect utilization of other health services among ALHIV, e.g. SRH.

> *I had this adolescent, he was found HIV positive, went back home, told to come back, he wanted to come back but then at home the parents are like, 'no you're not HIV positive'. It's like they didn't want to accept so they refused him. Some it's the parents that stop them from going because of lack of information, they don't know about HIV and all, how you get it and all that (Nthudza, Adolescent Counselor)*

> *… some parents they don't want other people to find out that their children are positive and accessing medicines, the parent would rather collect medicines for the adolescent. So that child won't have access to other health services such as, including information, services such as lab services, because they have to check their CD4, the viral load, the liver function and all those clinical tests, so the mother will just say, 'no my son or my daughter went for holiday I'm collecting medicine for her', that creates problems especially for the adolescent living with HIV. So we have so many of them failing on treatment because they're parents are shielding them, they don't want them to go to the health facility (Vincent, Program Officer)*

Social support is associated with positive health outcomes, including improved adherence. As an important source of social support for ALHIV, participants described lack of treatment-related social support from caregivers as a barrier to adherence and engagement with treatment services. The practice of treating adolescents as adults, e.g. not providing much support or guidance, contributes to lack of social support.

> *You know adolescents the problem that we have in our setups, where they come from, we think if a child is about 12 years or so, we think it's grown up enough to be responsible over his or her own health, so we let go to support them. Most of these adolescents are not supported. And the mothers will just say, 'have you taken your drugs?' What answer do you expect, yes or no, a child will just say yes, you see, there's lack of support in their homes normally (Chikondi, Nurse)*

> *But I think in our culture if you are 16-year-old, you'll be considered to be an adult, which is not the case. So you do not have anybody to support you… we'll not pay attention to this adolescent, because we're thinking it's an adult they'll know. So they will not have any support to make sure that, they take their drugs, they make sure that they exercise, to make sure that they eat right, because we've got this*

> *conception to say, no they are adults, and that's just our culture, we tend to perceive adolescents as an adult (Chibulu, Program Coordinator)*

Similarly, unstable home environments were described as a determinant of lack of treatment-related social support. Adolescents moving homes usually as a result of the death of their caregiver(s) and not being looked after or supported as well as they were, was described as negatively affecting engagement with treatment. This lack of support is exacerbated when caregivers are unaware of the adolescent's HIV status.

> *Socially, you know we have some of the adolescents who've lost their parents and now they have to move from one home to the next. That also has an effect, they may not be looked after like the way they're parents used to. Others still find better homes but a good number it's not easy. If you look at most families they're struggling just with their own children, so if they are to take on extra children, it's not easy looking after such children. Then others will still face stigma in these homes, where they are taken in (Kangwa, Doctor)*

> *And then sometimes you have kids that are mobile, you know, um, maybe one parent died or both parents and then now they're in this person's hands, after 3 months they're moved to Uncle so-so, after two days they are moved into another place for care, those ones also find it difficult to access the medication, because maybe the person they first lived with when they were identified to be HIV positive understood the situation, the other several homes that they are going to do not even know that they're on medication (Matt, Deputy Director of Programmes and Operations)*

Peers significantly influence the behaviors of adolescents. Participants described peer pressure to engage in risky behaviors such as drug and alcohol abuse as a barrier to adherence, e.g. forgetting. They acknowledged that adolescents engage in such activities to fit in with their peers.

> *Some it's the issues of peer pressure to do with alcohol, some will go and drink alcohol they'll forget to drink their medication (Kalolo, Project Coordinator)*

> *…they would like to do what other people are doing, which they can't do like, smoking ,drinking, you know. When you are taking ARVs, if you drink you are going to forget, if you smoke dagga you're going to forget, so it means you are going to miss taking your drug, so these adolescents they would like to do the same things that they're friends are doing, as a result they stop taking drugs (Tiwonge, Nurse)*

The personal relationship theme highlights how close relationships with individuals that are part of the social networks of ALHIV affect their engagement with treatment. Participants described factors ranging from lack of/poor HIV status disclosure to peer pressure, which significantly affect retention and adherence to ART among ALHIV.

Health care system- ***"they're overcrowded, the staff capacity is limited"***

Health care system refers to factors affecting the experiences of ALHIV with accessing health services and their HIV treatment. Distance to health facilities and the cost of transportation were described as challenges to accessing health services.

> ***Interviewer:*** *And in your experience, can you tell me about some of the reasons why HIV positive adolescents drop out of care or poorly engage in care?*
> ***Chibulu:*** *Long distances to health facilities, although the Ministry of Health has tried to solve that by creation of health posts (Program Coordinator)*
>
> *There's an issue of transport cause most of these, the background where they're coming from, they're unable to afford certain things (Alfred, Program Coordinator)*

Participants described the operational hours of health facilities as a challenge to accessing health services with clinics operating at hours inconvenient for adolescents, e.g. those attending school.

> *I think in almost all the health centers, adolescents are given one day, positive adolescents, to be attended to. I think most of the hospitals*

> *its Thursday. This is also adding to the defaulter rate, most of these are in schools, so which means they cannot come on Thursday. So if you do not have a buddy, anybody to send to go and collect the drugs for you and you're in school, you default (Chibulu, Program Coordinator)*

> *As well as, uh, the convenience because, I'll tell you a young person supposed to be in school, maybe I can talk of someone who is between age of 16 to 19 they're supposed to be in college, then within those times you're supposed also to get their medication (Kalolo, Project Coordinator)*

Staff shortages at health facilities is another challenge that affects the experiences of ALHIV when accessing health services. Staff shortages were described as causing long waiting times to obtain services.

> *So one of the experiences is that, um, young people tend to not attend their review meetings because of timing in terms of, um, the congestion in health facilities as well as the staffing in health facilities (Kalolo, Project Coordinator)*

> *They do not like waiting, adolescents don't like standing in the queue. When you go for ART, you go as early as 05, you will be leaving the clinic at 16 hours, you know. You'll find the nurses are not even there, the time they are coming, the adolescents is in the queue, they will have to wait until 16 hours for them to get the ARVs (Chibulu, Program Coordinator)*

Staff shortages were also described as affecting the quality of services received by ALHIV. Participants described health facility staff as not having enough time to spend on individual clients, which affected their ability to properly counsel ALHIV.

> *The problem with our government facility is they're overcrowded, the staff capacity is limited. People don't have time to sit and counsel… to sit and you know like, counselling takes a lot of time, depending on what the issues are, so they don't have that time to sit the whole day and you know, sit, let somebody cry before them, blah blah blah blah, they don't have that amount of time (Matt, Deputy Program Director)*

> *…a place like X* Hospital is very busy, when you go to ART department it's crowded and they are overwhelmed. So you find clinicians that are very busy and they're tired. Right now they have about three doctors sponsored by the Ministry of Health and one that is being sponsored by CDC, that was brought in, so four who are seeing about 300 plus clients a day, uh, adolescent included. So we do have one-on-one counselling because those are the kinds of things that normally they lack at the clinic due to, um, long queues or, um, the crowds, there's too many people there waiting to be attended to, so they don't really have that much attention (Chibulu, Program Coordinator)*

Poor attitudes among health facility staff was described as a challenge to accessing SRH services. Participants acknowledged that adolescents fear the judgmental attitudes of health facility staff and/or being refused such services which deters them from seeking them.

> *…in areas where you do not have, you know, child friendly spaces, or youth friendly health services, um, the service itself is a barrier because you have health care provider who may be very judgmental. They'll be like, 'no I think this is not for kids, this is a service for adults' (Lazarus, Senior Technical Officer)*

> *Overall a lot of young people report not being able to access testing, or condom, or contraceptives because they're afraid of being judged by the health professionals. If you put yourself in the shoes of someone who lives in a village and has only one health center to go to, and is afraid that the nurse is gonna tell your mom at the market that, um, you got tested for HIV, or that you requested condoms, or God forbid you want the pill or an IUD because you're a girl and you don't want to get pregnant, then It's not just your mom, everyone will know you're having sex, and if everyone will know you're not gonna get married, and you know, it's a lot of things (Beatrice, Communications and Advocacy Officer)*

Poor attitudes among health staff was also described as a barrier to engaging with HIV treatment services.

> *One of the reasons why adolescents are not visiting the health centers is nurses' attitudes and one of the reasons why adolescents*

> *default is just the nurses' attitude, they're not welcoming (Chibulu, Program Coordinator)*

Participants described the lack of adolescent specific health services at health facilities as a challenge to access and engagement with health services among adolescents.

> *Not all communities are serviced by mobile outreach and sometimes adolescents feel health facilities are not friendly enough so on their own becomes a challenge just to walk into a facility. There aren't so many adolescent friendly activities that can attract them and make them feel friendly at any facility, so that is also a barrier (Benson, Clinician)*

> *…I've done some work in the ART clinics, they don't have any specific, um, services just for the adolescents. We hear that in one queue you'll have uncle, grandparents, me the 10-year-old, a neighbor, and it's literally written ART quarter, so everybody knows what you've gone to access. I think there's still a lot of discrimination, just by virtue of having a facility that's attending to all age groups in one corner. I think that alone would be a challenge for the young people (Chibeka, Senior Program Manager)*

The health care system theme highlights challenges ALHIV face with accessing health facilities and their experiences obtaining services. Participants described distance to health facilities, inconvenient health facility hours, staff shortages, poor health facility staff attitudes and lack of AFHS as barriers to access and utilization of health services. These factors make it difficult for adolescents to access health services and significantly affects engagement with HIV treatment.

Perceptions of treatment failure

When discussing adherence challenges among adolescents, it was noted that some participants conceptualized adolescents as "defaulting" or "failing" on treatment.

> *when they're just children they usually take medication without knowing why, then there's that transitioning period when they get to know why they're taking medication, how they take it, they respond differently. Some respond good and treatment continues properly, some they respond in a negative way, treatment is disturbed. Some even start failing on treatment (Thando, Social Worker/Counselor)*

> *Okay, there are a lot of challenges, like working with them, trying to help those, especially most of those that are defaulting, they don't adhere, they don't accept their status, so it's quite a challenge. You will actually talk to them, tell them the do's and don'ts, they will accept but then you, they'll make you think they've accepted, they'll pretend around you and yet they'll be defaulting behind your back. So, it's quite a challenge trying to follow them up, just making sure they are on the right track (Nthudza, Adolescent Counselor)*

> *A lot of them are defaulting on treatment. Um, so I think they could still, um, find ways to ensure that these young people are following through because, these days to be very honest most of the people who you find, um, have died of AIDS or something, it's literally because of not taking their medication, it's rarely because they're taking their medication (Chibeka, Senior Program Manager)*

The attitudes and language used by healthcare providers in the clinic and community settings to describe adolescents experiencing such challenges may contribute towards further adherence challenges, especially if health care providers are not sympathetic to the lived experiences of these adolescents.

Community context- *"Some people are still stigmatizing people with HIV"*

Community context refers to social aspects of the context in which ALHIV live, including attitudes, widely held beliefs and neighborhood characteristics that affect the health and wellbeing of ALHIV.

Poverty related factors such as poor nutrition and lack of educational opportunities affect the wellbeing and development of ALHIV. Participants work with vulnerable communities struggling to access basic needs and described poor diet as a result of food insecurity as affecting the wellbeing of ALHIV, e.g. malnutrition and adherence to treatment.

> *…not all of them have, um, proper diets where they come from. You'll find most of the girls that we've been engaging with, when you just look at them you see that they are sick, despite them being on ARVs. Some of them since birth, but then they look sick, and most of it has to do with where they are coming from, their diet is poor (Chibulu, Program Coordinator)*

> *…there's an issue of poverty, kept on mentioning that, uh, a number of factors that comes in. The diet, a number of these homes we've visited, I think you discover that the diet is not, you know, sometimes they only will have one meal per day. And sometimes a child will say, since I'm weak, I'm hungry I won't take medication unless after I eat. Meaning you are told you have to take every day 12 hours you decide to skip cause you haven't eaten, you feel weak… These are things that they need but as an organization our hands are tied, we can only get to listen to what they need, they want but even nothing much we can do, except you know reporting back to the government (Alfred, Program Coordinator)*

In addition, lack of educational opportunities as a result of limited household financial resources negatively affects the wellbeing of ALHIV. Participants described lack of school fees for continued education as a threat to the development and future of ALHIV e.g. by preventing adolescents from achieving their potential and improving their lives.

> *The needs are school, some adolescents they come from very poor families. Even if they finish school, some of them they go up to Grade 7, Grade 8, they've got no one to support them to go ahead, some even to colleges. When you finish your Grade 12 you haven't' really done much, you need to go to college. So you find that some of them they can't go to colleges because they don't have anyone to support (Tiwonge, Nurse)*

> *…so like education is a need because it will help them stand in the future. So this, already going through the transition in the process, understanding about your status, they have issues and then there's no education. It's a need which at least it helps them to think of other*

> *things, it helps their mind to change, transform, they'll be thinking about the future, having a career, it helps them to have less thoughts about this about that. Education to help them be empowered (Thando, Social worker/Counselor)*

Social and cultural norms were described as barriers to adolescents learning about and accessing SRH services. Such norms discourage open dialogue about SRH issues and concerns and contribute to low uptake of SRH services, e.g. family planning.

> *We have a culture where sexual activities are for adults so with that, uh, mostly these guys are denied information on sexuality, they're denied access to condoms. There was debate which took place, uh, 'no these guys cannot have access to these things because of the culture aspect'. Everyone thinks these are children, we should concentrate on school, these are children who should not be thinking of sexual activities (Thando, Social worker/Counselor)*

> *The other thing is the cultural aspect, whereby there are already norms to say, no young people are not supposed to get condoms, you're not supposed to get contraceptives, different contraceptives apart from condom, then also, it's just the notion of, um, what word can I say, an African way of life where culture plays an important role, so meaning, if young people don't have access to these services HIV will go up (Kalolo, Project Coordinator)*

Participants also described faith and traditional healing practices as barriers to adherence among ALHIV.

> *Some they've gone to churches where they've been told that you are healed. Yeah, the pastor has prayed upon me and I've been told that I've been healed. Yeah, until they get sick and they come running back here (Tiwonge, Nurse)*

> *We have a huge problem with faith healing and alternative care. So there's a lot of people who we condemn like at an institutional level that ride on the wave of how well ARVs are working to tell you that by praying for you, by spraying you with herbal tea, by making you take a soup or, by whatever, um, you'll get better and you'll stay well. But if you've been on medication for 10 years, and your viral load is*

> *suppressed often if you take the instant test, the ELISA (enzyme-linked immunosorbent assay), you know the, the 20 minutes test or the, um, oral test, uh, it shows negative. And so very often, the priest or the pastor, or the faith healer, the traditional healer, will tell you, 'drink this tea and come back in a month', in a month your viral load is still suppressed because you've been taking ARVs for so long that it takes a while before your viral load goes up. And so after a month they give you an oral test and they tell you, 'see the oral test is negative so my tea cured you from HIV, you're not taking drugs and you're drinking my tea and you're still HIV negative', so boom. We know this, but a lot of people don't, and especially adolescents. Adolescents are so easily tricked into this because, it feels like the easy way out to a problem that would be overwhelming otherwise. You know, and so a lot of them tell you, 'I went to a faith healer, I got the herbal tea and I got cured and now I am fine' (Beatrice, Communications and Advocacy Officer)*

HIV-related stigma is prevalent and significantly affects the health and wellbeing of ALHIV. Fear of stigma and discrimination was described as negatively affecting adherence, with adolescents missing doses of their medication to prevent disclosure of their status. This challenge is particularly salient for adolescents in boarding schools.

> *I hear them complain about is discrimination and stigma in their homes, especially in the community. Because in their homes, there are those only the parents know, some they're siblings don't know, their cousins and all don't know, so it's quite a challenge. I have some that complain, maybe they go for a holiday, where they've gone, they don't know that they are on medication, so it's quite difficult to even take your medication (Nthudza, Adolescent Counselor)*

> *The other challenge is those who are in boarding schools, they are not able to freely take their drugs because in boarding schools you know it's just this big place and everyone is there, so they fear every day they're being seen, what are you taking? What are you taking? Some people are still stigmatizing people with HIV, so they don't feel that they should come out and let everybody know, especially them being at school, they fear to be stigmatized. So sometimes they will go maybe for a day or so without taking, if they're friends are around they won't take, as a result some of them are failing on treatment because they are not adhering well to treatment (Tiwonge, Nurse)*

Participants also described fears of anticipated stigma as contributing to the decisions of adolescents to not disclose their HIV status. They acknowledged adolescents wanting to maintain relationships with friends and romantic and/or sexual partners and avoid discrimination.

> *Some will tell you, no I'm thinking the moment I disclose this person's going to leave me, I'm going to lose influence in the group, everyone will think I'm not important in this group (Thando, Social worker/Counselor)*

> *Even their sexual partners, they are in very active, sexually active relationships and sometimes they don't even use protection, they'll tell you they don't use condoms but they won't disclose to their sexual partners. They fear the consequences, others are abandoned, others may even experience violence like yeah, so it's not easy for an adolescent to share their status honestly speaking (Kangwa, Doctor)*

The community context theme highlights the influence of the social context and commonly held views and beliefs on the health behaviors and health outcomes of ALHIV. Participants described poverty-related factors, social and cultural norms, faith and traditional healing and HIV-related stigma as negatively affecting access and utilization of health services and ART adherence.

Public policy- *"the age of consent is too much"*

Public policy refers to national and local regulations, policies and laws that affect the health and wellbeing of ALHIV, e.g. health service provision. The lack of widespread availability of third line ARVs was described as a challenge to offering adequate treatment options for ALHIV, with participants experiencing significant challenges obtaining and treating adolescents who require third-line ARVs due to their expense.

> *It is difficult for those that are failing drugs to be put on more advanced regimens because for them to be switched from second line to third line, it means government has to procure more medicines that may be expensive. But again it is the right of every adolescent or*

> *young person, even adult to have access to health services vis-a-vis HIV treatment, so the cost shouldn't really be a barrier, government has a responsibility to procure those drugs (Vincent, Program Officer)*

> *…third line are of course really expensive, and so far, there's no capacity to provide for a large number of people when it comes to third line ARVs, so that's a problem (Beatrice, Communications and Advocacy Officer)*

Participants described the Zambian government's reliance on external funding for ARVs as a challenge to future medication availability and emphasized the importance of finding more sustainable ways of funding the country's HIV/AIDS response in the long-term.

> *…as a country much of the budget is supported by the cooperating partners, I think over 75% is supported by external donors, so government has to invest more, we have to see a real investment in terms of budget support for the ART program (Vincent, Program Officer)*

> *Zambia heavily relies on external funding for supply of ARVs, 85%, so it's really crucial to make sure, especially cause adolescents today, if you take a photograph of today in Zambia, you see adolescents who are virally suppressed and have all the chances of dying a natural death of whatever reason, or car crash at an older age, but if you shift this photograph into 5 years' time, it depends on how the Zambian government is able to maintain what now is being paid for by external donors, because if the Zambian government can only pay for half those ARVs, it means that half of the people will be left without ARVs and will eventually die of HIV (Beatrice, Communications and Advocacy Officer)*

Current SRH policies are a barrier to access and utilization of SRH services among ALHIV as they require parental or guardian consent for adolescents below the age of 16 to access services such as family planning and HIV testing.

> *Then the other thing, the biggest for me in Zambia it's the age of consent, both for HIV as well as for sexual reproductive health, in terms of access cause the age of consent is too much (Kalolo, Project Coordinator)*

> *An adolescent who is 16 cannot give consent to have an HIV test unless you have a buddy or a caregiver that will give consent and we cannot tell you your results unless you have somebody. You know, we can only tell it to your mother or your auntie who can disclose (Chibulu, Program Coordinator)*

> *…its currently at 16 in Zambia, so it means that if a 14-year-old girl goes to the health facility and she wants to know her HIV status they can't provide that test without the parent's consenting, neither can a 15-year old. So I think the issue with consent is a huge barrier… It's the same with family planning, you can't provide family planning to an adolescent below the age of 16 (Chibeka, Senior Program Manager)*

As reflected in the above quotes, the age of consent makes providing SRH services to adolescents difficult, especially for adolescents who might not want their parents or guardians to know. Participants expressed frustration with such policies due to their awareness of the need for such services among adolescents.

The public policy theme highlights the role of policies in determining service availability, accessibility and utilization among ALHIV. Participants described difficulty obtaining third-line ARVs, government reliance on external funding of ARVs and restrictive SRH policies as significant barriers to improving HIV treatment and SRH outcomes among ALHIV currently and in the near future.

As described through the five organizing themes of individual experiences, personal relationships, health care system, community context and public policy, this global theme explored how factors existing at different socio-ecological levels affect the health and wellbeing of ALHIV. These factors also highlight the important role of the social environment in producing and maintaining risks to the health and wellbeing of ALHIV.

7.2.2 Comprehensive context-driven interventions addressing the various needs of ALHIV are needed

Despite the progress made in improving access to HIV care and treatment services, there are still many important challenges that need to be addressed to improve treatment outcomes and access to health services, including SRH among ALHIV. Participants described various approaches or actions that can be taken to better support ALHIV. This theme will be organized according to two organizing themes: multi-faceted approach and health service delivery (Table 7-3).

Table 7-3: Comprehensive context-driven interventions addressing the various needs of ALHIV are needed

Global theme	*Organizing themes*	*Basic themes*
Comprehensive context-driven interventions addressing the various needs of ALHIV are needed	Multi-faceted approach	• Address various social determinants of health • Involve diverse stakeholders
	Health service delivery	• Convenient clinc hours • Inclusive health services • More AFHS • Responsive SRH policies

Multi-faceted approach- *"its work done equals to zero if you give me powerful medicine and I don't even have food to eat"*

Participants described the need to explore and address the diverse factors that affect treatment engagement and the wellbeing of ALHIV beyond individual adherence. They described the need to address psychosocial factors impacting ALHIV.

> *What government can do is just take down statistics and do maybe a study and just find out which area, which compound, who needs support, and what type of support. So that as they are coming to get medication, they are able to be identified and be given that kind of*

> *support they need. Could be food or what because, the focus has been so much on adherence, come to the clinic get medication but there's no much follow up on how is the kind of environment at home, are they able to afford even a meal. Because for me I feel its work done equals to zero if you give me powerful medicine and I don't even have food to eat (Alfred, Program Coordinator)*

> *...we need to come up with programs that will look both at the economical, at the social, as well as the health, because they're intertwined, you cannot look at one and leave out the other. Our practice here working with the social as well as coordinating the clinical, it has just shown me that they're interlinked. So I think merging of program, making sure that we offer a service that's comprehensive when it comes to addressing issues of the adolescents (Chibulu, Program Coordinator)*

> *…there's that psychological impact that most programs or interventions tend to ignore. Much emphasis has been on, adhere to treatment, take drugs every time, I mean the environment where that young girl or young boy lives really matters. There's that psychological impact that has a bearing on health outcomes in general (Vincent, Program Officer)*

The importance of involving various stakeholders to improve the health and wellbeing of ALHIV was also described. Participants described their experiences of involving caregivers in programs to equip them with information and skills to better support their child and training health facility staff with the knowledge and skills to deliver AFHS.

> *…this project has made us realize that we also have to look at the homes where these girls come, they come from the community, so how do we engage with their guardians. So we do invite them here so that we just enlighten, certain things that they don't see, that we see when we engage with the girls here. So we do have meetings or just normal trainings with their parents, with their teachers, for those who go to school, also with the community at large, so that we are able to share with them certain information that they don't really see, that we see from our end, that way we are bettering the lives of these girls in these communities (Lilian, Program Coordinator)*

> *In the government facilities like, for here in Zambia I think the health workers should be trained more in how to handle adolescents (Matt, Deputy Director of Programmes and Operations)*

As significant stakeholders, they also described involving ALHIV in the planning, implementation and evaluation of interventions in order to promote the development of appropriate and acceptable programs that are responsive to their needs.

> ***…** most of the projects that are meant for adolescents are being led by the adults. So you do not have adolescents themselves expressing their challenges, they're not given those platforms. So in making policies, you have adults making policies for adolescents, you know, and we are making those policies, um, through our experience, but we do not have any idea what they're going through because we grew up in a, different adolescent world, so I feel its lack of platforms where adolescents are heard, policies that are made when adolescents are not represented (Chibulu, Program Coordinator)*

> *You might think that what we're doing is best for them but, do we involve them in our planning, when we're coming up with these programs do we involve them, or only involve them when we want to lobby for money, then when money comes then we forget about them, we don't implement? So also adolescents themselves are a good source to know like, how are the services, what would you like to be added to these services, um, how can we improve the services, that feedback is very very important if you're going to give good service to the adolescents but I've seen them being involved at a certain level, maybe planning, coming up with ideas but when it comes to implementation they're left out (Kangwa, Doctor)*

> *…we need to involve more of the adolescents themselves to talk about their problems, and the adolescents themselves I think, um, to lead the process. In coming up with solutions that are affecting adolescents themselves. I think if we did that we may achieve much more than what we're doing (Lazarus, Senior Technical Officer)*

The multi-faceted approach theme highlights the need to target the social determinants of health and include multiple perspectives in addressing the health and wellbeing of ALHIV. Participants described the need to explore the various psychosocial factors that affect the treatment and wellbeing of ALHIV and involve significant actors or stakeholders to better address the needs and improve the support provided to ALHIV. This approach promotes the development of comprehensive interventions addressing multiple interconnected factors which have the potential to significantly improve the health and wellbeing of ALHIV.

Health service delivery- *“We need to see deliberate infrastructure...which is flexible to young people”*

Participants described the need for health facilities to be flexible and offer more convenient hours of operation or weekend clinics to cater to ALHIV as adolescents often experience difficulty with accessing health services due to being at school during regular hours of operation.

> *I think that ideally now, we’re trying to push to have clinics that are more user friendly, not only for adolescents but also for people who work during the day. So if the clinic is only open during school hours you have to skip school to go to the clinic (Beatrice, Communications and Advocacy Officer)*

> *We need to see deliberate infrastructure whereby someone can go to the facility and get medication maybe on a weekend, which is flexible to young people. So if that’s not done that becomes a drive for HIV, meaning that young person won’t access the medication, in the end they’ll stay like that and then they’ll pass the HIV to maybe their sexual partner or something like that (Kalolo, Project Coordinator)*

The need for inclusive health facilities with services catering to all ALHIV, especially those living with disabilities was described. Some of the challenges faced by this population with accessing HIV treatment and SRH services are illustrated in the quotes below.

> *…you can go to the hospital, you’ll find an adolescent who’s deaf, who’s blind, and you have no idea on how to handle them. Because I can’t do sign language, we don’t have braille, so how am I supposed to counsel them, how will we talk to them, so there are those*

> *limitations. And for a government facility it's a must have when we come to the hospital. We must find a counselor whose able to sign, just in case you get somebody who can't talk. Braille, just in case you get somebody who cannot see. So the system needs a lot of improvement to make sure that they are inclusive (Chibulu, Program Coordinator)*

> *…people living with disabilities are always very stigmatized when it comes to sex. And so a lot of people with disabilities try the first time and then don't go back again, because they're like I've been treated so poorly by the nurse, or the midwife, or the doctor saying, 'Oh I didn't expect it from you', 'Oh you are doing this', the problems grow exponentially when you're living with a disability... But the chances are that if you go to a clinic and you can't speak, they're gonna turn you away because they don't know what you want, and if you can't write, you also can't write what you want (Beatrice, Communications and Advocacy Officer)*

Participants also described the need for more health facilities offering AFHS. They acknowledged how such services can improve uptake of health services and improve treatment outcomes among ALHIV.

> *And then we also have these, some of the facilities that will not offer sexual reproductive health services. So in such cases you find they [adolescents] are referred to another facility, and you know if within the facility they find it hard to access what about those that have to get the service outside their facility. So I think make the [adolescent] services more available, even in places where they're not (Kangwa, Doctor)*

> *So what we need is spaces, when we say space, not a small corner in the health facility for adolescents, there's need, so we need big spaces, with information there and staff employed. A counsellor employed to make sure that they handle adolescents, proper documentation, proper follow-up (Chibulu, Program Coordinator)*

> *…intensifying adolescent friendly health activities, if a lot more of such can be opened up it could really help (Benson, Clinician)*

The need for SRH policies that are responsive to the needs of ALHIV and the local context were described. Participants stressed that current government policies restricting access to SRH services are not responsive to the realities and experiences of adolescents. They also described the fear of violating policy as a barrier to the provision of such services on the part of HSPs like themselves.

> *…for the government we need to be supported in terms of policy. We need to find ways of collaborating and coming up with, um, policies, also guidelines, that have the best interest of the adolescent from all angles. I know for me I want to offer this, but how about the other part, what does the law say, if I offer this, is it a crime, so we need that harmonization when it comes to services being given to these adolescents (Kangwa, Doctor)*

> *…we know that most of them are sexually active or some of them potentially are living with HIV through transmission from the mother for example but without the consent we can't go ahead and provide the test. There are countries like South Africa, Swaziland that have reduced their age of consent. This is something that we're discussing as a technical working group so that we can influence government to see if it can be reduced (Chibeka, Senior Program Manager)*

This theme explored suggestions for health care system-related changes to improve uptake of health services and encourage treatment engagement among ALHIV. Participants described health facilities offering more convenient hours of operation, being inclusive, increasing AFHS and the development and implementation of more responsive SRH policies. Such changes can transform the experiences of adolescents at health facilities and promote positive health behaviors.

As described through the two organizing themes of multi-faceted approach and health service delivery this global theme explored opportunities for the government and its partners to better approach and support ALHIV. The suggested actions largely focus on structural factors, calling for the development of comprehensive and relevant interventions addressing the unique needs and concerns of ALHIV. Such changes are critical to improving health service delivery and encouraging the uptake of health services in this population.

7.3 Discussion

The findings from this chapter address the gap in the literature concerning the perceptions and experiences of health care providers working with ALHIV in resource limited settings. It highlights barriers at various socio-ecological levels that affect the lived experiences of ALHIV and undermine their engagement in the HIV care continuum across the life course. The study found considerable overlap in perspectives of challenges affecting access to health facilities and adherence to medication between HSPs and adolescents (Chapter 5 and Chapter 6). Both parties described individual, interpersonal, community and structural factors that affect treatment engagement. My findings differ from other studies on the experiences of adults living with HIV in SSA that found significant discrepancies between health care provider and patient perspectives on barriers to adherence (Bogart et al., 2013, Moucheraud et al., 2019).

Participants described beliefs, attitudes and experiences of adolescents that negatively affect adherence and wellbeing. HSPs described similar self-stigmatizing beliefs concerning limited capabilities of PLWH compared with those not living with HIV held by ALHIV e.g. fears of early death, which affected their adjustment. Barriers such as size and/or taste of ARVs, side effects, engagement in social activities with peers and alcohol abuse were similarly described by both adolescent and HSP participants as barriers to adherence. HSPs described other individual factors affecting adherence that were not mentioned by adolescent participants but have been reported in other studies among PLWH. These include pill burden (Nachega et al., 2014, Hanna et al., 2014, Cohen et al., 2013, Chen et al., 2017, Salleh et al., 2018); treatment fatigue (Bukenya et al., 2019, Claborn et al., 2015, van Wyk and Davids, 2019); lack of information and/or understanding of HIV treatment (Bukenya et al., 2019, Galea et al., 2018, Ahmed et al., 2019) and improvements in health (Azia et al., 2016, Shubber et al., 2016, Croome et al., 2017), which have also been associated with non-adherence in other health conditions including hemophilia and depression (Greenley et al., 2010, De Moerloose et al., 2008, Ho et al., 2017, Maddox et al., 1994, de Dassel et al., 2017). Other individual level barriers described by health care providers in adult studies in SSA that differ from my findings include laziness, fear of lifelong medication and not feeling sick/asymptomatic (Nhassengo et al., 2018, Loeliger et al., 2016, Earnshaw et al., 2018).

Participants described the influence of the social environment or the conditions in which ALHIV live as affecting their health and wellbeing. They described the influence of poverty on the diet and education of adolescents. Poor diet was described as a barrier to adherence (Anema et al., 2009, Croome et al., 2017, Bukenya et al., 2019, Biadgilign et al., 2009, Heestermans et al., 2016, Pettitt et al., 2013) and is associated with poor health and development outcomes among children and adolescents (Seligman et al., 2010, Lassi et al., 2017, Jyoti et al., 2005, Fiese et al., 2011, Aurino et al., 2020, Weinreb et al., 2002). Food insecurity also increases the risk of HIV transmission and re-infection as it is associated with increased sexual risk-taking behaviors (Anema et al., 2009, Frega et al., 2010). Participants described many ALHIV who are out of school or not progressing to secondary or tertiary education as a result of limited financial resources. This was also observed among older adolescent participants, with many not in school or having had to drop out due to being unable to afford tuition (Kimera et al., 2020a, Abubakar et al., 2016, Ramaiya et al., 2016). Education is associated with numerous benefits including improved health outcomes (Raghupathi and Raghupathi, 2020, Zajacova and Lawrence, 2018) and improved prospects of employment (Filmer and Fox, 2014). These challenges highlight the important issues poverty raises for young people, e.g. lack of basic needs and opportunities and the potential negative impacts on their life course. Addressing the factors that trigger, maintain and exacerbate issues with engagement to treatment within the social environment may significantly improve the wellbeing of ALHIV (Petersen et al., 2013, Burgess, 2015, Hatcher et al., 2020).

Participants highlighted the key role played by caregivers in supporting the wellbeing of ALHIV and emphasized the importance of engaging them in efforts to support ALHIV. They described difficulties working with ALHIV as a result of caregiver behaviors that significantly influence treatment engagement. Unlike working with adults who are responsible for their own health, HSPs often have to work with caregivers when providing services to adolescents. They described caregiver lack of and/or poor disclosure of HIV status and caregivers blocking access to treatment as affecting adherence and retention in care among ALHIV (Biadgilign et al., 2009). Similar findings were reported by adolescent participants, highlighting the role caregivers can play in undermining treatment engagement along the care continuum. Findings from the literature on barriers faced by caregivers with disclosure of HIV status to children were discussed earlier in this thesis (Chapter 3) and include fears of negative emotional reactions (Mahloko and Madiba, 2012, Mandalazi et al., 2014, Vaz et al., 2010, Sariah et al., 2016); not knowing how or when to disclose (Britto et al., 2016, Doat et al., 2019, Vreeman et al., 2013); fear that their own HIV status might be exposed as a result of disclosure (Mandalazi et al., 2014) and fear that their child and/or themselves may be stigmatized by others (Mahloko and Madiba, 2012, Sariah et al., 2016). Participants expressed their frustrations with caregivers who did not disclose in a timely manner as this significantly affected the services they could provide to ALHIV and their wellbeing.

Lack of social support from caregivers was also described as significantly affecting engagement with treatment, e.g. adherence (Galea et al., 2018). Participants described working with many ALHIV who have experienced/experiencing home instability, e.g. moving from home to home as a result of being orphaned (Leyenaar, 2005), which contributes to lack of social support and treatment disruption. The literature suggests that the experience of multiple family transitions can negatively affect child development (Fomby and Cherlin, 2007, Gaydosh and Harris, 2018). ALHIV need continuous but evolving support to promote their wellbeing and engagement with treatment. As caregivers play a significant role in the lives of ALHIV, participants stressed the need to engage them in interventions to improve health outcomes in this population.

Stigma was described as significantly affecting the adherence of ALHIV, and was also described as contributing to non-disclosure of HIV status. Similar findings were reported by adolescent participants. Participants described social and cultural norms that are barriers to ALHIV learning about and accessing SRH services (Abuosi and Anaba, 2019, Thongmixay et al., 2019, Ndayishimiye et al., 2020, Nmadu et al., 2020). These norms were described as making the provision of health services to adolescents more difficult, especially since these norms are often held by individuals with decision-making power. Norms regarding treating adolescents as adults have also contributed to adolescents being provided with services designed for adult or pediatric populations (Mburu et al., 2013). Faith and traditional healing practices were also described as barriers to adherence (Croome et al., 2017, Bukenya et al., 2019, Azia et al., 2016, Heestermans et al., 2016, McKinney et al., 2014, Tunje et al., 2021). Despite some of the reported consequences of the use of traditional medicine on HIV treatment outcomes (Peltzer et al., 2010, Littlewood and Vanable, 2008, Heestermans et al., 2016), traditional health practitioners can play an important role in the treatment and management of HIV as a result of their unique social position within communities (Homsy et al., 2004).

Participants highlighted how structural barriers to health service utilization and health service provision to adolescents plays a crucial role in shaping the treatment experiences of ALHIV, especially adherence and retention in care. Health care system factors including distance to health facilities, inconvenient clinic hours of operation, long waiting times and poor attitudes among health facility staff were described as negatively affecting engagement with treatment by both HSPs and adolescent participants. Participants emphasized the need to establish more AFHS at health facilities, which are associated with improved retention and treatment outcomes among ALHIV (Lee et al., 2016, Zanoni et al., 2017, Zanoni et al., 2022) and provide adolescent friendly training to health care providers (Pettitt et al., 2013). Regarding health care provider perceptions of treatment failure, the study highlighted problematic language used by this population in discussions concerning adherence challenges faced by ALHIV, with similar findings reported in other studies among health care providers caring for this population (Lanyon et al., 2020). Similar to findings from Chapter 5, the attitudes and language used by HSPs to describe ALHIV experiencing adherence difficulties (e.g. “failing”), may contribute to nondisclosure of adherence challenges and potential treatment disengagement (Lanyon et al., 2020, Burns et al., 2020, Bernays et al., 2017).

Age of consent to access SRH services was described as a significant barrier to the provision of health services to adolescents. Participants described their willingness to provide such services and emphasized their need however, they worry about the potential consequences of violating existing policies. These policies restrict access to such services and make controlling the HIV epidemic amongst adolescents more difficult, as they contribute to low testing rates and late diagnosis among adolescents (Kidman et al., 2020, McKinnon and Vandermorris, 2019, Fox et al., 2013). Participants emphasized the need for the government to consider revising such policies and make them more responsive to the local context as they have the potential to increase uptake of SRH services and improve SRH outcomes in this population (Sam-Agudu et al., 2016, McKinnon and Vandermorris, 2019). This is crucial, as during adolescence as described in previous chapters, individuals may begin to experiment and engage in romantic and/or sexual relationships.

Participants described challenges with providing treatment to ALHIV as a result of limited government funding of HIV/AIDS treatment and care programming. They described difficulty providing third-line ARVs to adolescents in need due to their high cost, which is problematic because ALHIV have been found to poorly adhere to treatment (Armstrong et al., 2018, Reif et al., 2020) and are at increased risk of treatment failure (B Nachega et al., 2011, Mbuagbaw et al., 2015). The importance of ensuring access to more advanced regimens is highlighted in the findings of the adolescent study which discussed the experiences of two adolescents on third line regimens. Other structural level barriers described by health care providers in adult studies that differ from my findings include receipt of disability grants and ARV stock-outs (Coetzee et al., 2011, Moucheraud et al., 2019).

Participants expressed a sense of dejection when describing the perceived challenges ALHIV face. They understand the challenges faced by ALHIV and what needs to be done to improve their experiences but are unable to adequately address their needs due to limited capacity and opportunities to act (Burgess, 2015). They expressed a sense of powerlessness as a result of their limited spheres of influence which are further exacerbated by various structural factors. They recognize a need for structural changes within the health care system and deflect responsibility for action to the government, as they feel limited in their actions and effectiveness to improve the lives of ALHIV without government action. They call upon the government to create a more enabling environment to improve service provision to ALHIV by giving them the opportunity and resources to cater to the needs of ALHIV. They highlight the need for social welfare support; increased health staff capacity at health facilities; expansion of AFHS, including convenient clinic hours and revised health policies concerning adolescents, demonstrating the need for comprehensive and multi-sector approaches to promote the health and wellbeing of ALHIV (Petersen et al., 2013). Participants feel these kinds of system level changes are necessary to improve treatment outcomes and experiences with treatment among ALHIV.

Conclusion

Building upon the findings from the previous chapters, the findings from this chapter provide insight into HSP understandings of the lived experiences of ALHIV and the challenges they face accessing and engaging with treatment, demonstrating that HSPs are familiar with the challenges ALHIV face with treatment engagement (Chapter 5) and with challenges that arise across their life course, including engagement in risky behaviors and self-disclosure of HIV status (Chapter 6). Findings highlight that factors at various levels of society impede engagement with the HIV care continuum, particularly adherence and retention in care and provide suggestions to improve adolescent engagement and treatment outcomes. It also shows that HSPs feel a sense of dejection due to the restrictions placed on their ability to act and provide services to ALHIV as a result of the limiting social landscape. In describing their experiences, it highlights unique issues faced by HSPs in the provision of services to adolescents, including difficulties working with caregivers and restrictive health policies. Finally, it demonstrates the urgency of creating enabling social environments to support the health and wellbeing of ALHIV across the various socio-ecological levels of influence (Burgess, 2015, Hatcher et al., 2020, Vitalis and Hill, 2017, Petersen et al., 2013, Hardee et al., 2014). This chapter addressed the gap in the literature on the experiences of HSPs providing health services to ALHIV in resource limited settings (especially in Zambia) and included perceptions of HSP from both clinical and community-based settings and also comparatively explored their perceptions with the experiences of ALHIV, which very few studies among PLWH in limited resource settings have done (Moucheraud et al., 2019).

Chapter 8 Reflections, contributions and recommendations on research into the lived experiences of ALHIV in resource limited contexts

8.1 Introduction

The aims of this thesis were to explore the experiences of adolescents across the HIV care continuum, including interpreting barriers and facilitators to accessing and engaging in HIV care and treatment; identify and analyze psychosocial factors affecting the lived experiences of ALHIV, and propose interventions to address challenges faced by ALHIV and improve treatment engagement and outcomes. The continuum of care was used as an organizing framework to explore the experiences related to HIV treatment and care and the challenges faced by ALHIV and the SEM informed the exploration of factors shaping the experiences of ALHIV across the HIV care continuum. In this final chapter, I discuss the key findings and contributions of the analyses in this thesis, discuss the theoretical and methodological contributions, present two conceptual models based on study findings to enhance understandings of the lived experiences of ALHIV in resource limited settings, discuss limitations of the study and propose recommendations for practice and intervention, policy and future research.

8.2 Key findings and contributions to the literature

Systematic mixed studies review on the self-disclosure experiences of ALHIV

Findings from the SMSR (Chapter 3) that explored the self-disclosure experiences of ALHIV in SSA found that various psychosocial factors influence disclosure of HIV status among ALHIV. Findings reveal low rates of self-disclosure among ALHIV with many believing that their HIV status should be kept secret. The review also found that ALHIV disclose their HIV status to diverse groups of individuals in various contexts, including friends, sexual and/or romantic partners, teachers and health care workers. However, most reported disclosure experiences were to friends with alarmingly low disclosure to sexual partners. The review also identified positive (e.g. encouragement, medication reminders, etc.) and negative (emotional distress, stigma, etc.) consequences of disclosure that influenced engagement in treatment and psychological health. Diverse barriers to self-disclosure were identified including feelings of shame, caregiver instructions to not disclose, fear of rejection, abandonment and low self-efficacy to disclose with findings suggesting that various risks associated with self-disclosure may vary depending on the type of relationship. Many of these barriers were also identified in the adolescent and HSP chapters. A facilitator of disclosure included having a trustworthy relationship with the person adolescents chose to disclose to. The findings highlighted gaps in the self-disclosure literature, including lack of uniformity in the application of disclosure terminology, few studies describing facilitators and motivations for disclosure and interventions targeting self-disclosure among ALHIV.

The main contribution of this study is that it provides a summary of the literature on the self-disclosure experiences of ALHIV in SSA. To the best of my knowledge this review is the first SMSR exclusively focusing on the experiences of ALHIV aged 10-19 in SSA, the highest burden region. The findings of this review enhance understandings of the self-disclosure experiences of ALHIV by providing an understanding of the experiences and factors that affect disclosure of HIV status among ALHIV that can be used to inform intervention development. It also identified gaps in the literature requiring further investigation, specifically motivations and facilitators of disclosure among ALHIV. Finally, from the discussion of identified barriers among ALHIV I suggested a typology indicating that the perceived risks associated with disclosure vary by type of relationship and that the various risks may manifest differently.

Experiences with the HIV care continuum

Chapter 5 discussed the findings from the analysis of the perceptions and experiences of ALHIV with the HIV care continuum, highlighting challenges faced by ALHIV from discovery of HIV status to engagement with HIV treatment and care. The findings discuss experiences surrounding learning of HIV status, coping with HIV diagnosis, challenges with accessing HIV care and treatment, adhering to treatment and managing anticipated stigma. Findings revealed that ALHIV experienced emotional (e.g. shock, anger, etc.) and psychological (disbelief, confusion, etc.) consequences of disclosure which affected their adjustment and treatment and initiation of ART. Concerning post-disclosure experiences, the finding that ALHIV were treated better than their siblings without HIV and were shown extra care and special attention (e.g. increased care and attention, better commodities, etc.) contradicts findings from other studies in the literature that describe unfair and harsh treatment in the household (Kimera et al., 2020b, Kip et al., 2022).

Findings also described various psychological framing strategies (e.g. acceptance, positive outlook, etc.) and social support from a variety of sources (e.g. family, peers, health workers and NGOs) that helped ALHIV cope with their HIV diagnosis. In relation to acceptance, participants acknowledged that forgiving their mother/parents for infecting them with HIV facilitated acceptance, which has not been reported in the literature. Also, the finding that gender norms facilitate adherence among male participants contradicts other studies in the literature that report masculine gender norms as a barrier to engagement with HIV care and treatment (Horter et al., 2017, Mbokazi et al., 2020, Aliyu et al., 2019).

ALHIV in this study face diverse psychosocial challenges with both accessing and engaging in HIV care and treatment. These challenges included medication-related factors; clinic-related factors and challenges managing adherence in the context of everyday life. Some of the barriers to treatment engagement were found to vary by clinic attended. A unique finding of the study is that caregiver denial/disbelief of participant HIV status is an important barrier to linkage and retention in treatment, which was also confirmed in the analysis of HSP perspectives (Chapter 7). Poor physical clinical infrastructure was also identified as barrier to engagement with care, a unique finding that to my knowledge has not been identified in the adolescent literature and highlights the need for clinics to consider the holistic experience adolescents have when seeking care.

Findings contribute to the limited literature on the experiences of ALHIV on third line ART regimens, revealing that ALHIV on third line regimens had similar experiences to other participants however they seemed to experience greater difficulties (e.g. psychological, economic, etc.) with adherence and retention in care. In addition the findings contribute to the limited literature on perceptions of treatment failure and how it influences the adherence experiences of ALHIV. Findings showed that the fear of less than perfect adherence and/or being seen to be "non-adherent" by both caregivers and health care providers may negatively influence adherence. Findings also contribute to the limited literature on the perceptions and experiences of ALHV with transition to adult care, illustrating the abrupt and unstructured nature of the transition process, the lack of adolescent preparation and the lack of guidance and/or standardized transition protocols. Finally, the findings highlight the pervasiveness of HIV-related stigma which influences much of the experiences and behaviors of ALHIV and the strategies used by ALHIV to cope with stigma, including the unique findings that ALHIV engage in stigma related behaviors as a coping mechanism to avoid unintentional disclosure of their HIV status.

Life course approach to understanding experiences of ALHIV

Chapter 6 discussed findings from the analysis applying a life course approach to examine the experiences of ALHIV, addressing the gap in the literature using the approach. The findings demonstrate that ALHIV experience various events, transitions and emergent challenges as they navigate living that shape their lived experiences. Findings demonstrate that most participants experienced poor health for an extended period of time that negatively affected their quality of life and wellbeing however, these experiences also facilitated HIV diagnosis and adherence to treatment. Findings emphasized how participants lives significantly changed after learning their HIV status including the need to adopt new behaviors and stop certain behaviors. Findings also suggest that over time ALHIV experience shifts in their perspectives, moving from immediate fear-based concerns to more hopeful and optimistic thoughts about their future. Another important shift that was identified was the transition to self-management of treatment, as participants described moving from dependence on caregivers to taking on increasing responsibility for their treatment and care.

Findings highlight that the socio-economic context limits the opportunities of participants, particularly their ability to complete their education. A couple of adolescents had even dropped out in primary and/or secondary education as a result of parental loss. Findings also revealed that in discussing the death of a parent, participants emphasized the pragmatic ramifications of the experience (e.g. hardships experienced and limited opportunities for their future) and not the more emotive aspect which is often not reflected in the literature on the experiences of ALHIV (Skovdal et al., 2009). The experience of stigma within the home and school context was another challenge participants identified that contributed to their experience of internalized stigma. This finding coupled with the findings described in the previous chapter (Chapter 5) regarding special treatment at home suggest that ALHIV are more likely to experience harsh and discriminatory treatment as a result of their HIV status in homes where their caregivers are not their biological parents, contributing to the limited literature on how family structure may influence the psychosocial wellbeing of ALHIV in resource limited settings.

Findings of the analysis also contribute to the limited literature on the self-disclosure experiences of ALHIV, especially the gap concerning motivations and facilitators of disclosure (Chapter 3). Findings demonstrate that ALHIV disclose their HIV status to family, friends and romantic partners for various reasons indicating that despite living in a setting where HIV is highly stigmatized, ALHIV are willing to disclose their HIV status in order to facilitate their engagement with treatment and protect their wellbeing. The finding that disclosure to sexual partners is associated with intentions to engage in safer sex contradict findings from other studies in the literature (Toska et al., 2015, Dempsey et al., 2012).

Perceptions of Health Service Providers on the experiences of ALHIV

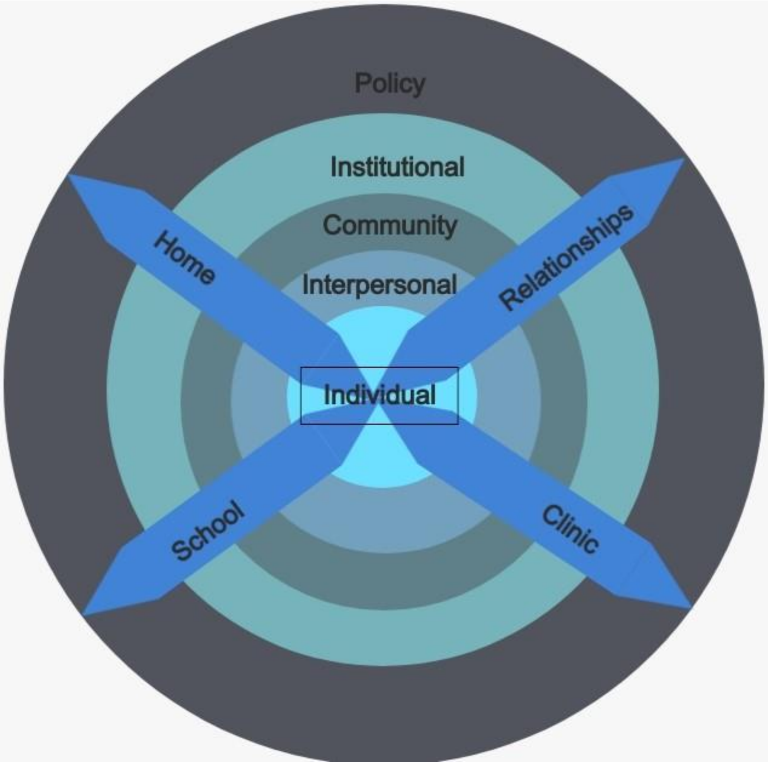
Chapter 7 discussed findings from the analysis examining the perceptions of health service providers (HSPs) from both clinical and community-based settings on the experiences of ALHIV with engagement with the HIV care continuum. Most of what is known about the experiences of HSPs in SSA are based on adult studies. HSPs identified challenges faced by ALHIV across various socio-ecological levels, including individual, interpersonal , community, institutional and public policy that undermine adolescent engagement with the HIV care continuum and affect their lived experiences. These findings revealed that HSPs were very knowledgeable of the experiences of ALHIV and the challenges they face, with significant overlap with the findings described in the adolescent chapters (e.g. barriers to adherence and accessing health care services). My findings differ from other studies among adults living with HIV in SSA which found significant discrepancies between patient and health care provider perspectives concerning significant barriers to ART adherence (Moucheraud et al., 2019, Bogart et al., 2013). Findings also described HSP suggestions concerning how to better support and engage ALHIV in treatment and care services which include taking a multi-faceted approach to addressing the needs of ALHIV and improving health service delivery. However, the findings highlight that HSPs feel helpless in their ability to respond to the needs of ALHIV as a result of the limiting social landscape in which they work. The findings of this study address the gap in the literature concerning the perceptions and experiences of HSPs working with ALHIV in resource limited settings and specifically contribute to understandings of the experiences of HSPs working with ALHIV in Zambia, highlighting the socio-ecological factors that are barriers to improving treatment engagement. To my knowledge, this is also one of the few studies to explore the perceptions of community based NGOs alongside those of health care workers concerning the experiences of ALHIV in resource limited settings.

Application of the SEM

The findings of this thesis contribute to the limited literature applying the SEM to understand the experiences of ALHIV aged in resource limited settings (Mburu et al., 2014b, Enane et al., 2020) with findings indicating that factors across the levels of the SEM affect the engagement of ALHIV across the continuum of care and hamper efforts of health service providers to address their needs and challenges. The SEM informed the exploration of the various factors shaping the experiences of adolescents across the HIV care continuum and supported the development of a contextualized understanding of the psychosocial factors affecting the lived experiences of ALHIV, a central aim of this thesis. It informed the data collection, analysis and interpretation of findings in facilitating the identification of multi-level factors that contribute to the lived experiences of ALHIV, especially the decisions and behaviors affecting treatment outcomes. It informed the development of the topic guides and prompted me to ask open-ended questions about the influence of individual, interpersonal, health care system and community factors on the experiences of ALHIV and those of HSPs.

During the data analysis process, I mapped out the experiences and contexts to the relevant levels of the model and interpreted their impacts as barriers and/or facilitators of treatment engagement among ALHIV. The study findings demonstrate that the lived experiences of ALHIV are shaped by multilevel, dynamic and overlapping factors within the social environment that influence their experiences across the life course. Multiple psychosocial factors, including facilitators and barriers were described as shaping the experiences of ALHIV across socio-ecological levels from the SMSR and the adolescent and HSP analyses. HSPs also emphasized how such factors significantly restrict their opportunities to provide needed services to ALHIV. Based on the findings of this thesis I have developed an adapted SEM to describe the contextual factors affecting the lived experiences of ALHIV, including health decisions and behavior regarding treatment engagement and their wellbeing (Figure 8-1).

Figure 8-1: Adapted SEM of factors influencing health experiences of ALHIV in the context of HIV



Policy

-SRH policies

-ART policies

Institutional

Service environment:

-Health facility hours

-Waiting time

-Support services (e.g. support groups)

Quality of care:

-Patient-provider relationship

-Adolescent friendly health services

-Treatment availability (ART regimens)

Processes:

Disclosure of HIV status; treatment initation

Community

Environmental context:

-Distance to health facilities

-Poverty

Social context:

-Social and cultural norms

-HIV stigma

Relational

-Social support

-Non-disclosure of HIV status (antiicpated stigma)

-Peer influence (e.g. substance use)

-Social activites

-Negative consequences post disclosure of HIV status

-Caregiver influence (e.g. poor/lack of HIV status disclosure, controlling access to treatment and self-disclosure of HIV status)

Processes:

Disclosure of HIV status

Self-disclosure of HIV status

Individual

-Sociodemographics (e.g. age, SES)

-Health status

-Emotions/feelings

-Beliefs (e.g. treatment related, self stigma)

-Attitudes

-HIV knowledge

-Non acceptance of HIV status

-Treatment regimen (e.g. size of ARVs, side effects, pill burden, treatment fatigue)

-Faith and traditional healing practices

-Coping (psychological)

-Biographical experiences

-Everyday life activites

Processes:

Disclosure of HIV status

This model has five levels: individual, relational, community, institutional and policy that affect decisions and behaviors of ALHIV regarding their health and wellbeing in the context HIV treatment and care. It also indicates important processes that have implications for engagement in the HIV care continuum. The individual level includes individual characteristics and personal factors that influence decisions and behaviors and include sociodemographic profile, e.g. influence of age and socioeconomic status; emotions/feelings; attitudes; beliefs; health status; HIV knowledge; non-acceptance of HIV status; treatment regimen; faith and traditional healing practices; coping (psychological); biographical experiences (e.g. past and present life experiences) and everyday life activities (e.g. forgetfulness). An important process to consider at this level when examining experiences of ALHIV is disclosure of HIV status, including its circumstances and outcomes.

The relational level depicts factors related to the interpersonal relations adolescents have with individuals within their social network and their social behaviors. These include social support; non-disclosure of HIV status (associated with anticipated stigma); peer influence (e.g. substance use and risky sexual behaviors); social activities; negative consequences post-disclosure of HIV status, e.g. rejection, loss of friendships/relationships; caregiver influence, e.g. poor disclosure or non-disclosure of HIV status, controlling access to treatment and adolescent onward disclosure of HIV status. Important processes to consider at this level include disclosure of HIV status to the adolescent and self-disclosure of HIV status by the adolescent to others.

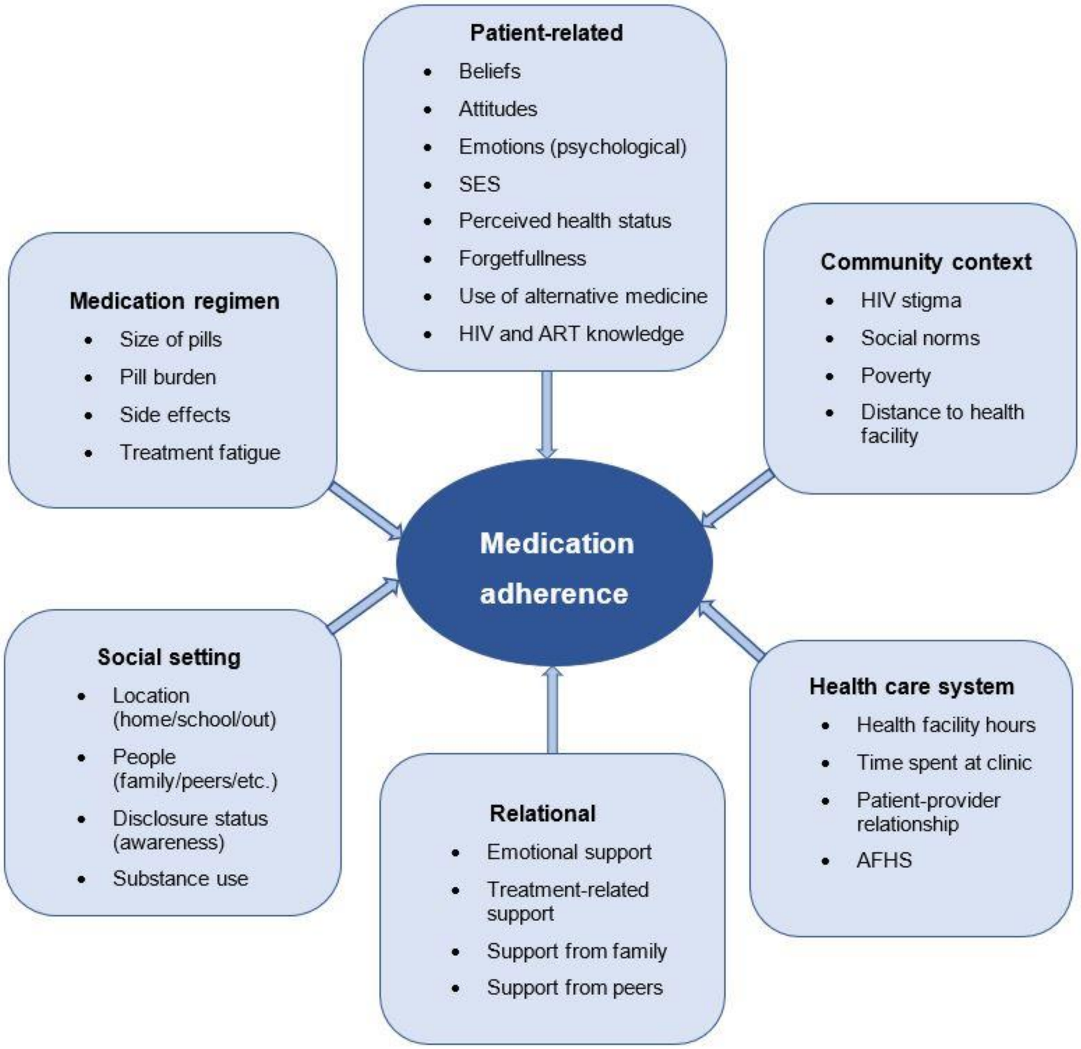
The community level refers to factors characterizing the context in which adolescents live e.g. characteristics of neighborhood/communities and includes distance to health faculties; impact of poverty (e.g. diet and education); social and cultural norms (e.g. adolescent seen as children vs adolescent seen as adult affect access to SRH information and social support) and HIV-related stigma. The institutional level describes factors related to the health facility and includes factors related to the service environment such as inconvenient clinic hours; long waiting times (e.g. crowded clinics, shortage of health staff); support services (e.g. support groups) quality of care (e.g. patient-provider relations, AFHS) and treatment availability (e.g. available ART regimens). An important process to consider at this level when examining experiences of ALHIV include disclosure of HIV status to the adolescent, as health care providers are often involved or can play a significant role in this process. The policy level includes factors related to national and local regulations and policies and includes SRH and ART policies. These various levels and factors interact to shape adolescent perceptions and experiences across their life course.

As adolescents have unique needs and experiences, there are specific contexts that may require special consideration when examining the experiences of ALHIV. The model suggests four key areas for consideration, including the home environment, relationships, school and clinic as findings from this study have demonstrated that they significantly influence adolescent decisions and actions. However, these may not be the only important contexts shaping adolescent experiences. The home environment significantly influences the wellbeing of ALHIV with findings showing that stigma in the home affected the psychological wellbeing of adolescents and those of low socio-economic status described financial constraints that affected their ability to access health services and education. Secondly, relationships with family and peers were shown to both positively and negatively influence adolescent decisions and behaviors. Thirdly, adolescents spend a lot of time at school where the atmosphere and relationships they have within it significantly influence their experiences, especially peer influence which was found to affect adolescent engagement in risky behaviors. However, other important points to consider include HIV stigma in the school context, including the language and behaviors used by teachers and administrators and the adherence difficulties experienced by adolescents.

Lastly, the clinic is a significant context as adolescent experiences accessing services and receiving treatment contribute to their engagement with treatment and care. The service environment, including the availability of services, how accessible or adolescent friendly they are and the quality of patient-provider relationships are important things to consider in this context. Each of these key contexts affect adolescent experiences across the levels of the SEM and present their own risks and challenges that interact and overlap. It is important that their effects are examined in the provision of services and development of interventions.

Based on the adapted SEM described above I propose a conceptual framework that describes factors influencing medication adherence decisions and behaviors among ALHIV (Figure 8-2). The model outlines six significant influences contributing to decisions regarding adherence to medication among ALHIV: Patient-related; Medication regimen; Community context; Health care system; relational and Social setting. Patient-related factors include beliefs; attitudes; emotions (psychological feelings); socio-economic status (SES); perceived health status; forgetfulness; use of alternative medicine and HIV and ART knowledge. Factors related to medication regimen include size of pills; pill burden; side effects and treatment fatigue. Factors influencing adherence within the community context include HIV-related stigma; poverty; social norms and distance to health facilities. Health care system factors include clinic hours; time spent at clinic; patient-provider relationship and availability of AFHS. Relational factors outline the types and sources of social support and include emotional support; treatment-related support and support from family and peers. Social setting factors refer to characteristics of the social setting that affect the likelihood of adherence and include location e.g. home, school, out and about; type of people present e.g. family, friends, strangers, etc.; disclosure status within setting e.g. awareness of their HIV status among those present and substance use. These factors are situational and may change depending on the social setting in which adolescents find themselves.

Figure 8-2: Conceptual framework describing factors influencing medication adherence among ALHIV



This model explaining factors contributing to adherence decisions and behaviors of ALHIV contributes to the literature as to the best of my knowledge there is currently no disease specific model of ART medication adherence for adolescents. The adapted SEM and my proposed conceptual framework are useful for informing future research into the lived experiences of ALHIV, especially treatment-related challenges e.g. adherence faced by ALHIV and the development of interventions to enhance treatment engagement in this population.

The models illustrate how the social environment affects the experiences of ALHIV, specifically their health decisions, behaviors and outcomes. They also depict how factors at various levels of influence restrict opportunities for engagement with health services, highlighting significant barriers to controlling the HIV epidemic among adolescents. The findings of this study demonstrate that ART provision is not sufficient to turn the tide of the adolescent HIV epidemic and emphasize the need to address factors in the social environment that trigger, maintain and exacerbate risks and barriers across the life course. This is crucial to improving the health and wellbeing of ALHIV in resource limited settings as changes in the social environment will result in changes in the individual, leading to improved HIV treatment outcomes and wellbeing. The establishment of supportive social environments responsive to the needs of ALHIV is paramount due to the cumulative effect of factors across socio-ecological levels that adversely impact adolescent experiences across the care continuum. These environments should eliminate existing barriers and increase protective factors to promote healthy decision-making and behaviors affecting engagement in HIV treatment and the wellbeing of ALHIV. Such enabling environments would also support HSPs in the delivery of much needed services to ALHIV as they currently face significant structural barriers, e.g. human and material resources, SRH policies, etc. I hope that the adapted SEM and my proposed conceptual framework can be applied in understanding factors influencing the health and wellbeing of adolescents in other resource limited settings and inform future research and intervention development especially locally (e.g. Ministry of Health, NGOs, etc.)

Limitations of SEM application

Despite its utility for facilitating the understanding of the diverse factors affecting the experiences of adolescents beyond the short comings of more individual focused cognitive theories of health behavior, the model does not facilitate understandings of how factors at various levels cut across or interact, as described earlier in the thesis (Chapter 2). It can be hard to differentiate an individual factor from an interpersonal one due to the nature of the phenomenon or its associated effects and to assess where to intervene. Similarly, I found it challenging to locate certain factors in the SEM as they seemed applicable to more than one level. This led to having to make difficult decisions about where to place factors which in practice may have significant implications for policy and/or intervention development (Shiffman et al., 2016). For example, substance use can be understood to be an individual behavior however, in my findings it is described as an interpersonal (peer influence) or accepted social norm. Further research examining the factors and mechanisms operating within and between the various socio-ecological levels would provide some insight or guidance in dealing with issues concerning the inter-related nature of the levels and the mapping of factors. Despite its limitations the SEM suited the aims of this thesis as it is an accessible explanatory model for understanding factors related to health experiences and behaviors. The nature of the model enhances its accessibility and applicability for stakeholders involved in the development of policies and intervention development for adolescent health (Sanga et al., 2019).

Application of Social phenomenology

Schütz' social phenomenology approach was useful in examining the experiences of ALHIV, especially the identification of social factors, contributing to the literature on applied approaches taken to studying their experiences. The approach aims at understanding the lived experiences of everyday life and contributed to understandings of how the social environment affects the lived experiences of ALHIV. It also complemented the SEM guiding this thesis, contributing to a deeper understanding of factors affecting the lived experiences of ALHIV as the SEM is more descriptive in nature. Findings show that the four concepts of the lifeworld e.g. biographical situation, stock of knowledge, existential reasoning and intersubjectivity relate to factors across socio-ecological levels and are useful in understanding the various ways the social context affect the health decisions and behaviors of ALHIV. The concept of biographical situation contributed to reflections on the influence of personal experiences, both past and present affecting treatment and behaviors of adolescents. Stock of knowledge helped identify attitudes, beliefs and gaps in knowledge that affected experiences of adolescents and intersubjectivity helped reflect upon the influence of social interactions, including relations with individuals in the social network, social norms and publicly held beliefs, e.g. HIV stigma. Finally, the concept of existential reasoning facilitated the identification of barriers and facilitators to treatment and other experiences, e.g. disclosure of HIV status.

8.3 Limitations

The studies have a few limitations. Firstly only ALHIV accessing treatment services, living in urban areas and aware of their HIV status were included in the adolescent study, as a result the experiences of those not accessing treatment and/or living in rural areas and/or unaware of their HIV status may differ. Likewise the perceptions and experiences of HSPs in rural parts of Zambia may also differ. There is also a risk that I may have oversampled individuals who were more expressive and/or outgoing and more interested in sharing their experiences, especially with a stranger from overseas. Also, adolescents may have felt uncomfortable sharing sensitive information about their experiences that may have been personally stressful and/or challenging within the social context. For example, social and cultural norms that frown upon speaking openly about SRH. A few of the interviews were conducted in a mix of English and Nyanja which poses the risk of some meaning being lost in translation however this was minimized through the translation checking process described in 0. Ideally, a more comprehensive approach could have been taken involving transcription of the interviews in Nyanja and back-checking with more than one translator. However, due to study limitations, (e.g. finances(I conducted a smaller scale approach to check the validity of the translations. Due to the positive results of the translation checking process and the frequent lapses of participant responses into English, I am confident in the original translations.

The application of the lifeworld concepts of the social phenomenology approach was limited as they were applied to complement the SEM in exploring various factors on the lived experiences of ALHIV. The application of the life course approach was also limited because the decision to apply it was made post data collection therefore traditional data collection methods e.g. life history interviews were not conducted resulting in limited biographical data including on early life experiences and other potentially significant social, biological and behavioral factors that may have influenced the experiences and health of adolescent participants. Despite these limitations, findings from the application of the life course approach show that it is a useful framework to understand the experiences of ALHIV across the life course, especially events, experiences and challenges that emerge and have implications for the health and wellbeing of ALHIV. Future research should apply traditional life course methodology into examining how factors across the life course of ALHIV have shaped their lived experiences and health, as there is a paucity of data using this approach among ALHIV.

Despite the large number of interviews I was able to conduct with adolescent participants limitations include a lot of repetitive data which did not contribute new information and the inability to go into more depth which may have been possible with fewer interview participants. Fewer interview participants may also have enabled a more in-depth exploration and understanding of participant experiences as emphasis could have been placed on establishing a rapport with participants and conducting repeated interviews to follow up on certain points and examine others that may not have been covered previously (DeJonckheere and Vaughn, 2019).

Finally, a large majority of the adolescent sample were vertically infected (n=49), with the remaining unsure (n=2) of their infection route and due to ethical restrictions on sensitive research with children, I was unable to recruit younger adolescents into my study. Therefore the perceptions and experiences of horizontally infected adolescents and those of younger adolescents may differ. Nevertheless, the study has multiple strengths including the large adolescent sample; recruitment of adolescents and involvement of HSPs from multiple clinic and NGO sites; findings reflect the experiences of ALHIV in urban areas receiving treatment services at public health facilities and it highlights multiple opportunities to improve HIV treatment outcomes and promote the wellbeing of ALHIV.

8.4 Recommendations

The findings of this thesis highlight the need for interventions that target multi-level factors in the social environment that negatively affect the experiences of ALHIV in order to mitigate impacts on their health and wellbeing. These challenges must be addressed using a combination of approaches including educational, behavioral and policy interventions. Based on the findings from this study I discuss some key recommendations for practice, policy and future research in the following sections.

8.4.1 Recommendation for practice and intervention

During adolescence, adolescents may struggle with adjusting to the various changes they are experiencing and face increased risks for experiencing mental health issues, e.g. depression (Salmela-Aro, 2011). Consequently, adolescents coming to terms with an HIV+ diagnosis may face additional stressors and may be at increased risk for experiencing such mental health difficulties. It is important that clinics and community based organizations offer appropriate pre and post disclosure counselling programs or provide other means of supporting this population, as social support can help mitigate some of the psychosocial challenges faced by ALHIV (Lockwood et al., 2019). These programs should also target caregivers as findings revealed that caregiver behaviors can act ad barriers engagement in HIV care and treatment.

Managing adherence in everyday life was a significant challenge highlighted by participants. Targeted counselling sessions should be integrated into routine appointments in which any challenges experienced by ALHIV are discussed and health workers assist adolescents in identifying solutions to the challenges they face in their daily lives. It is important that the identified solutions are co-created, actively involving adolescents to promote acceptance and engagement. They should also take the stressors adolescents might be experiencing, e.g. busy schedules, after-school activities, family obligations and social life into consideration (McNeely and Blanchard, 2010).

Challenges with adherence also included the size and taste, side effects, and pill burden also continue to be barriers to adherence. It is important that attention is given to improving the drug formulations available to adolescents (Schlatter et al., 2016, Phelps and Rakhmanina, 2011), paying particular attention to what might be palatable to this population and improving access to pediatric ARV formulations as studies have found that adult pills are the main from of ART provided to children due to decreased availability of certain liquid formulations and child sized fixed dose combinations in many regions (Phelps and Rakhmanina, 2011),which is exacerbated in resource limited settings (Penazzato et al., 2018, Schlatter et al., 2016).

In recent years increasing treatment options have become available to PLWH. These options include new classes of ARVs using novel mechanisms to target the HIV virus (e.g. maturation and attachment inhibitors and broadly neutralizing antibodies) and new versions of classical ARV drugs have been reformulated (Cihlar and Fordyce, 2016, Cunha et al., 2021, Jefferys, 2021). These newer ARVs have high potency and resistance barriers which is important in treating PLWH with multidrug resistant strains of HIV with many mote in various phases of development (e.g. Islatravir, Lenacapavir, Azuvidine, etc.) (Cunha et al., 2021, Jefferys, 2021). Long acting (LA) ARVs are another important emerging treatment option with various forms of delivery including oral, injectable, implantable, etc. that are being developed and tested (Mantsios et al., 2021, Chandiwana et al., 2021). The first LA injectable treatment comprised of a combination of cabotegravir and rilpivirine has recently been approved in North America and Europe with approval in SSA underway (Chandiwana et al., 2021, Cunha et al., 2021, Thoueille et al., 2022).

LA ART has the potential to facilitate adherence and improve treatment outcomes among young people, especially ALHIV who experience significant challenges with daily ART adherence and have poor treatment outcomes (Foster et al., 2020). They also have the potential to reduce the experience of HIV-related stigma and other psychosocial barriers associated with adherence. Studies among young people has also found significant interest in using LA ART (Weld et al., 2019, Simoni et al., 2021, Simoni et al., 2019). In light of the significant adherence challenges faced by ALHIV, further research and investment should be made into LA ART with consideration given to the types of drug formulations and forms of delivery that would be most suitable in resource limited settings.

This study demonstrated that ALHIV are in need of support in balancing their daily life responsibilities with their engagement in treatment. Health care workers should use routine clinic appointments to examine the experiences of adolescents and help them identify solutions to specific adherence challenges they face in their daily lives. With this adolescent centered approach it is important that the identified solutions are co-created, actively involving adolescents to promote acceptance and engagement and should consider unique adolescent stressors, e.g. busy schedules, after-school activities, family obligations and social life (McNeely and Blanchard, 2010). Such services should be comprehensive and also focus on addressing the unique needs and contextual challenges facing ALHIV, as adolescents in resource limited settings face diverse and overlapping challenges that affect their wellbeing. Therefore, routine screening for individual, social and structural barriers to treatment engagement should be integrated into the routine management of ALHIV care to facilitate retention in treatment (Yehia et al., 2015).

The study findings also demonstrate the need for comprehensive health promotion interventions addressing common challenges experienced by adolescents including alcohol consumption, substance use, sexual relationships and other challenges unique to ALHIV, especially as they mature. Such programs should educate ALHIV about the potential negative consequences of engaging and/or not engaging in such behaviors to facilitate health decision-making. For example, it is important that ALHIV are well-informed about the potential risks involved in consuming alcohol and other drugs for their health and taught skills to help them manage or resist peer pressure, as peers significantly affect their behavior and willingness to engage in risky behaviors (Ivaniushina et al., 2019, Albert et al., 2013).

In light of the significant challenges ALHIV face with accessing and engaging in HIV treatment and care services and the concern with transitioning to adult care as expressed by this sample, there is a need for transition programs that gradually prepare and assist ALHIV with transitioning to adult care services. The adolescent participants in this study reported that there were no transition programs and there is also a lack of standardized national guidance or policy on the matter. Such transition programs should be introduced at clinics transferring ALHIV once they reach a certain age. These programs must equip adolescents with the necessary knowledge and skills to facilitate adjustment as transition of care is critical with many significant implications for treatment engagement (Dahourou et al., 2017). However, it is important that the readiness to transition for each individual adolescent is assessed as transition decisions should not be solely based on the attainment of a certain age but instead by a more personalized approach involving the assessment of an individual’s age of maturity, which bases decisions about transition of care on the individual characteristics and capabilities of each patient (O'Sullivan-Oliveira et al., 2014, Tepper et al., 2017).

Interaction and social support from fellow ALHIV positively influenced the health and wellbeing of adolescent participants in this study. As a result of the important benefits for the emotional wellbeing of ALHIV, it is important that peer support groups, mentoring support programs and/or other peer-led intervention models are scaled up and participation among ALHIV encouraged and programs made more accessible.

It is important that the structural barriers faced by ALHIV at the health facility level are addressed through deliberate infrastructure and practices that reduce barriers to access and utilization of health services and programs. This includes scaling up AFHS as many health facilities do not offer services targeting adolescents. Clinics should also facilitate adolescent engagement with treatment and reduce barriers to access and utilization of health services and support programs including, adjusting their hours of operation and/or introducing extra days or times that are convenient for adolescents. It is also important that the government ensure that clinics have the necessary resources to provide HIV care services. For example it is crucial that health facilities have a reliable supply of ARVs to avoid stock outs that contribute to disruptions in adherence, ART resistance, disengagement from care, morbidity and mortality (Gils et al., 2018). Clinics should also be staffed with individuals who are trained and have the knowledge and skills to work effectively with adolescents, as negative relationships with health care workers was highlighted as a barrier to treatment engagement. It is crucial that barriers to access and utilization of services are eliminated as adolescence is a “key period for the adoption of health behaviors relating to substance misuse, sex, diet and exercise, and the self-management of chronic disorders” (Viner et al., 2012, p. 1648).

Findings revealed that ALHIV struggle with disclosing their status for various reasons, including HIV-related stigma, lack of self-efficacy to disclose, etc. and they also report difficulty disclosing their status to sexual partners which has implications for onward transmission of HIV. Due to the potential benefits associated with disclosure, it is important that ALHIV are counselled about disclosure and provided with the necessary knowledge, skills and support. Findings also indicated that there is a lack of policy/guidelines addressing self-disclosure of HIV status for ALHIV despite such guidance existing for disclosure of parental and child HIV status (World Health Organization, 2011). Therefore, there is a need for the development of such guidance addressing self-disclosure counselling of ALHIV that outlines best practices and supports decision-making among key individuals and organizations (e.g. caregivers, ALHIV health care workers, governments and NGOs) and effective self-disclosure interventions for this population.

Additionally, increased efforts to address HIV-related stigma are needed. The findings of this thesis demonstrate that HIV stigma influences almost every aspect of the lived experiences of ALHIV from the moment of disclosure. Interventions are especially needed at the individual, interpersonal and community levels, as HIV-related stigma in these contexts significantly affected the psychosocial wellbeing of adolescent participants. It is crucial that the social environment is conducive to the health and wellbeing of ALHIV and a reduction in stigma would significantly improve the quality of life of ALHIV.

Lastly, there is also a need for more interventions targeting the adolescent HIV care continuum as studies have shown that such interventions targeting adolescents are scarce (Zanoni et al., 2022). Such interventions should be tailored to the unique and specific needs of ALHIV, including as they age across the life course. Findings from this study suggest that factors across socio-ecological levels affect the lived experiences of ALHIV and that ALHIV experience various events, transitions and emerging challenges across the life course which have distinct challenges and implications for HIV treatment and the wellbeing of ALHIV. It is crucial that adolescents are heavily involved in the planning and implementation of interventions as this would support the development of more acceptable and effective interventions that are responsive to the needs and experiences of adolescents.

8.4.2 Recommendations for policy

The findings of this thesis demonstrate that existing SRH policies are a significant barrier to adolescents accessing health services and engaging with the HIV care continuum, e.g. testing and linkage to treatment. SRH policies in Zambia currently restrict access to SRH services to individuals aged 16 and over without parental or guardian consent. This deprives many adolescents access to necessary health services leaving them at increased risk for adolescent pregnancies, engagement in sexual risk taking behaviors, etc. It is necessary that the Zambian government work to implement SRH policies that are responsive to the social reality and needs of adolescents and that comprehensive SRH information and services are made available and accessible to adolescents, as young people in SSA have many unmet SRH needs (Boonstra, 2007). Comprehensive SRH services can also be an important point of access for adolescents to test for HIV and be linked to care.

It is important that younger adolescents are able to participate in research, as their experiences may differ from those of older adolescents, which was cited as a limitation of this study. Therefore, there is a need for ethical guidelines to balance the need for and importance of such research with the potential harms. In doing so, the government must develop the necessary infrastructure to enforce and monitor research with younger adolescents and children whilst permitting their involvement in research studies aimed at improving their health, wellbeing, and access to services.

Disaggregated data on the health of adolescents is poor (Mburu et al., 2013). It is important that the Zambian government and other national stakeholders routinely collect and monitor sex and age disaggregated data on adolescents aged 10-19 at both the national and sub-national levels. This will aid the assessment of the needs of adolescents as distinct from other populations, e.g. young adults; facilitate comparisons of health needs of adolescents in different stages of development and inform the development of interventions (Suzuki et al., 2016).

8.4.3 Recommendations for future research

Research into the impact of stigma on the experience of ALHIV is needed, as my findings suggest that stigma affects multiple dimensions of the lifeworld of ALHIV and significantly shapes their experiences. However, not much is known about adolescent experiences of stigma and how it affects their lives as much of the HIV-related stigma literature is based on adult studies. Research should examine the impact of stigma through the three mechanisms in which HIV-related stigma is theorized to affect PLWH, e.g. enacted, anticipated and internalized stigma. This will allow a more “nuanced” understanding of the effects of HIV-related stigma on the lived experiences of ALHIV and inform the development of interventions to improve their wellbeing (Earnshaw et al., 2013).

Additionally, there is a paucity of studies on the lived experienced of horizontally infected adolescents as most of the existing ALHIV literature focuses on vertically infected adolescents. Research into this population is needed as their experiences may differ. Also, future research on the experiences of ALHIV should explore the experiences of early adolescents. Much of the research on the experiences of ALHIV excludes this population which may be the result of ethical restrictions on their involvement in research, as I experienced. However, it is important that future research examine their experiences and compare them to older adolescents. Such research would be a valuable contribution to the literature and facilitate the development of effective interventions that target the unique developmental needs of these various adolescent populations.

There is also a need for more research examining and comparing the lived experiences of ALHIV across adolescence, especially longitudinal studies examining the experiences of adolescents over time. The results of such studies have significant implications for the treatment and care of ALHIV and intervention development. Such research should apply a life course approach which could lead to a better understanding of the wide range of factors influencing the health of ALHIV and their trajectories across the life course, contributing to the identification of key areas for intervention to improve the health and wellbeing of young people living with HIV.

Finally, there is a need for more intervention research focusing on ALHIV. This population faces numerous psychosocial challenges that have significant consequences for HIV treatment outcomes and their wellbeing however, there are very limited interventions targeting this population (Casale et al., 2019, Murray et al., 2017, Shaw and Amico, 2016). Interventions targeting the psychological needs of ALHIV are especially needed as adolescents are at increased risk of experiencing mental health issues (Bhana et al., 2020, Vreeman et al., 2017).

Concluding thoughts

The findings of this thesis contribute to the literature on the lived experiences of ALHIV in Zambia and enhance understandings of the challenges facing ALHIV in resource limited settings. It demonstrates that the engagement of ALHIV in HIV care and treatment is heavily determined by the socio-ecological environment, including dynamic, interactive and multi-level factors that warrant a contextually based approach to addressing the challenges faced by ALHIV. The findings have shown that to better engage adolescents with HIV care and treatment, it is important that the lived experiences of adolescents, including the challenges they face are understood especially among policy makers and individuals serving this population. Findings have demonstrated that while improving and strengthening health service delivery to this population is important and should be prioritized it will not be sufficient as other factors beyond treatment and the control of adolescents significantly shape the experiences and behaviors of ALHIV. Therefore, it is crucial that interventions target multi-level factors with multi-faceted approaches to create enabling social environments for adolescents to flourish, which include addressing the socio-ecological factors that increase the risks of poor engagement in treatment among ALHIV across the life course.

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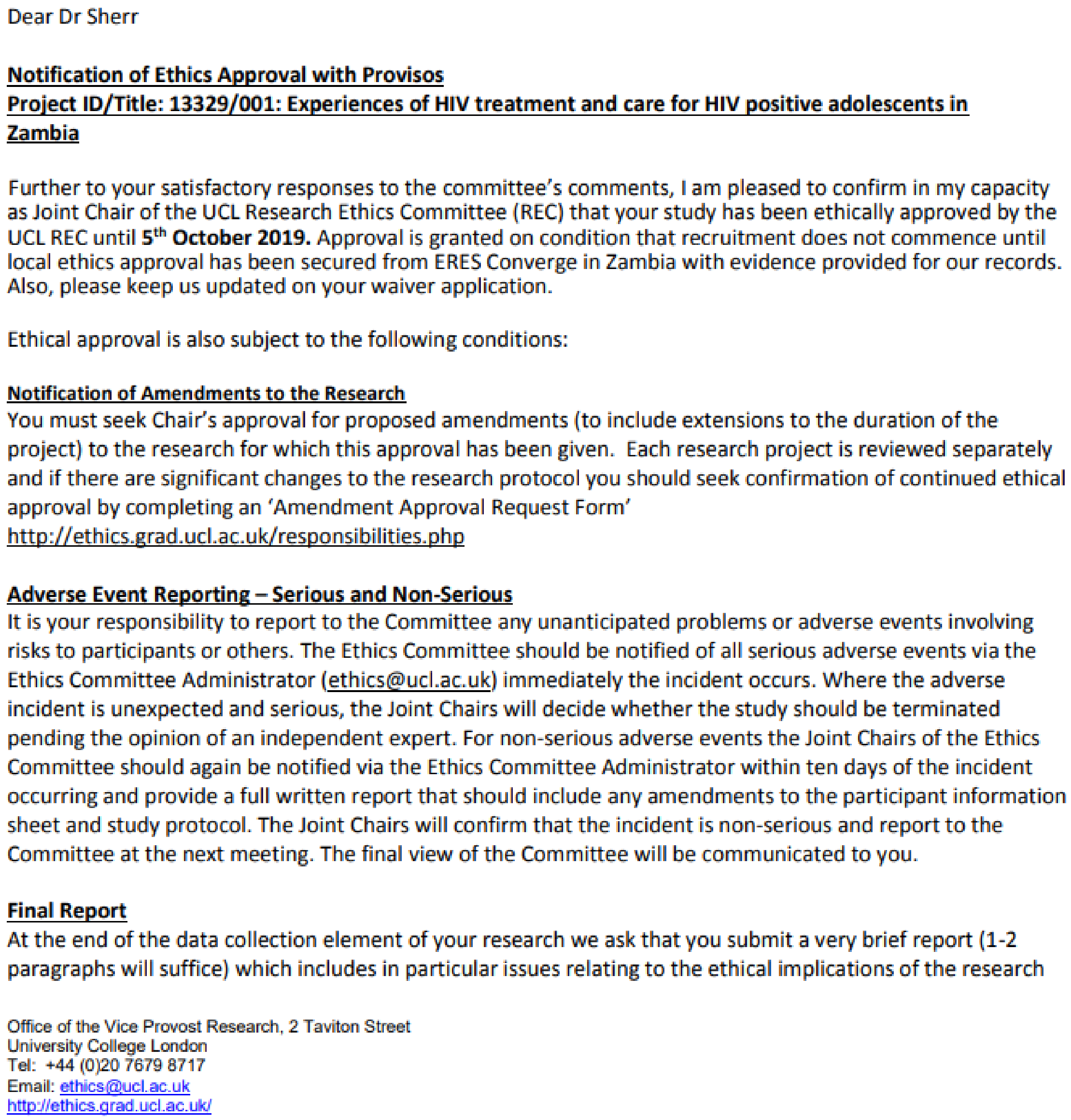
Appendix A : Ethical approval



Dear Dr Sherr

Notification of Ethics Approval with Provisos
Project ID/Title: 13329/001: Experiences of HIV treatment and care for HIV positive adolescents in Zambia

Further to your satisfactory responses to the committee's comments, I am pleased to confirm in my capacity as Joint Chair of the UCL Research Ethics Committee (REC) that your study has been ethically approved by the UCL REC until **5th October 2019.** Approval is granted on condition that recruitment does not commence until local ethics approval has been secured from ERES Converge in Zambia with evidence provided for our records. Also, please keep us updated on your waiver application.

Ethical approval is also subject to the following conditions:

Notification of Amendments to the Research
You must seek Chair's approval for proposed amendments (to include extensions to the duration of the project) to the research for which this approval has been given. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing an 'Amendment Approval Request Form'
http://ethics.grad.ucl.ac.uk/responsibilities.php

Adverse Event Reporting – Serious and Non-Serious
It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator (ethics@ucl.ac.uk) immediately the incident occurs. Where the adverse incident is unexpected and serious, the Joint Chairs will decide whether the study should be terminated pending the opinion of an independent expert. For non-serious adverse events the Joint Chairs of the Ethics Committee should again be notified via the Ethics Committee Administrator within ten days of the incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Joint Chairs will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

Final Report
At the end of the data collection element of your research we ask that you submit a very brief report (1-2 paragraphs will suffice) which includes in particular issues relating to the ethical implications of the research

Office of the Vice Provost Research, 2 Taviton Street
University College London
Tel: +44 (0)20 7679 8717
Email: ethics@ucl.ac.uk
http://ethics.grad.ucl.ac.uk/

i.e. issues obtaining consent, participants withdrawing from the research, confidentiality, protection of participants from physical and mental harm etc.

In addition, please:

- ensure that you follow all relevant guidance as laid out in UCL's Code of Conduct for Research: http://www.ucl.ac.uk/srs/governance-and-committees/resgov/code-of-conduct-research
- note that you are required to adhere to all research data/records management and storage procedures agreed as part of your application. This will be expected even after completion of the study.

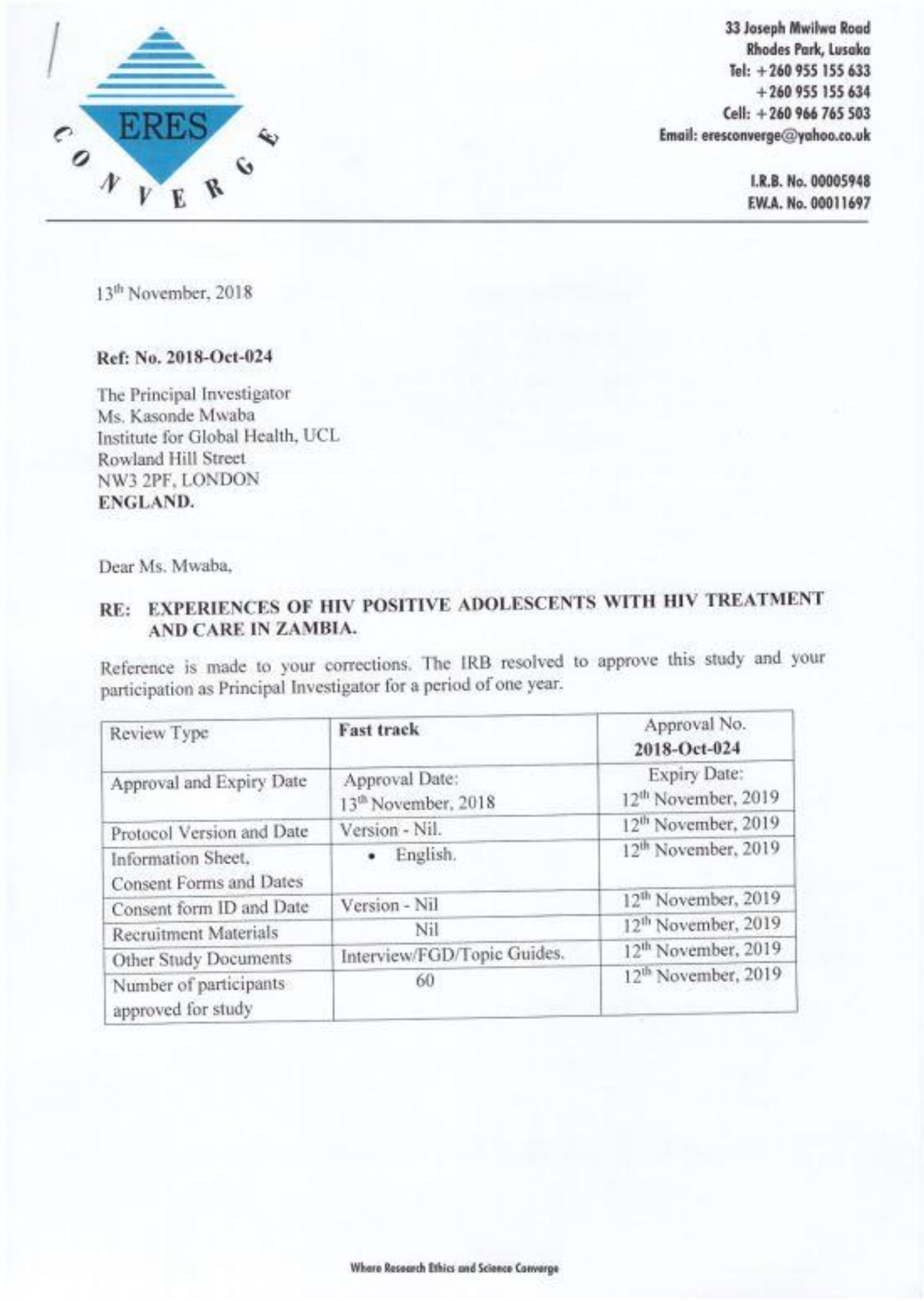
With best wishes for the research.

Yours sincerely

[redacted]

Dr Lynn Ang
Joint Chair, UCL Research Ethics Committee

Cc: Kasonde Mwaba



ERES CONVERGE

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I.R.B. No. 00005948
F.W.A. No. 00011697

13th November, 2018

Ref: No. 2018-Oct-024

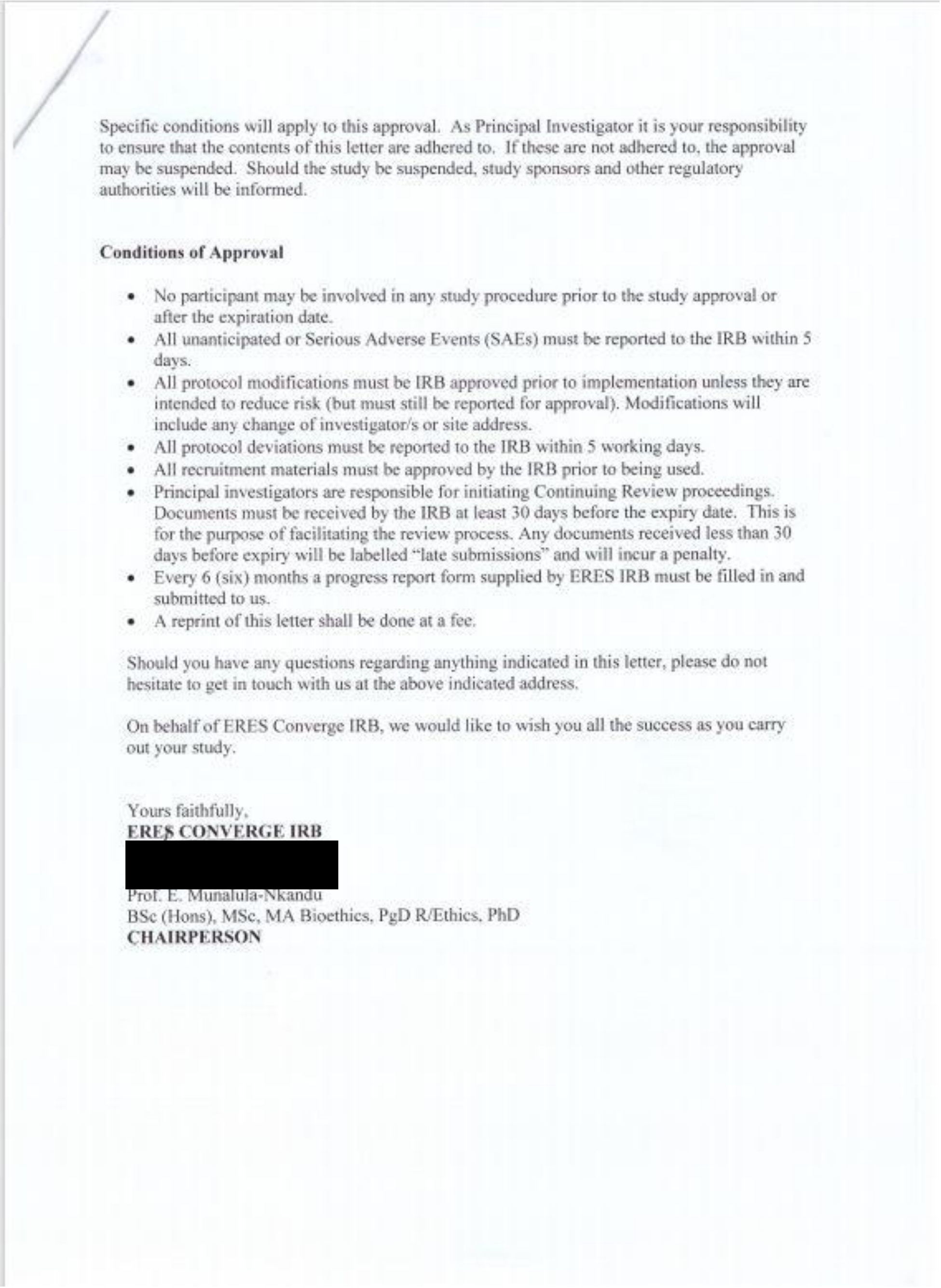
The Principal Investigator
Ms. Kasonde Mwaba
Institute for Global Health, UCL
Rowland Hill Street
NW3 2PF, LONDON
ENGLAND.

Dear Ms. Mwaba,

RE: EXPERIENCES OF HIV POSITIVE ADOLESCENTS WITH HIV TREATMENT AND CARE IN ZAMBIA.

Reference is made to your corrections. The IRB resolved to approve this study and your participation as Principal Investigator for a period of one year.

Review Type	**Fast track**	Approval No. **2018-Oct-024**
Approval and Expiry Date	Approval Date: 13th November, 2018	Expiry Date: 12th November, 2019
Protocol Version and Date	Version - Nil.	12th November, 2019
Information Sheet, Consent Forms and Dates	• English.	12th November, 2019
Consent form ID and Date	Version - Nil	12th November, 2019
Recruitment Materials	Nil	12th November, 2019
Other Study Documents	Interview/FGD/Topic Guides.	12th November, 2019
Number of participants approved for study	60	12th November, 2019



Specific conditions will apply to this approval. As Principal Investigator it is your responsibility to ensure that the contents of this letter are adhered to. If these are not adhered to, the approval may be suspended. Should the study be suspended, study sponsors and other regulatory authorities will be informed.

Conditions of Approval

- No participant may be involved in any study procedure prior to the study approval or after the expiration date.
- All unanticipated or Serious Adverse Events (SAEs) must be reported to the IRB within 5 days.
- All protocol modifications must be IRB approved prior to implementation unless they are intended to reduce risk (but must still be reported for approval). Modifications will include any change of investigator/s or site address.
- All protocol deviations must be reported to the IRB within 5 working days.
- All recruitment materials must be approved by the IRB prior to being used.
- Principal investigators are responsible for initiating Continuing Review proceedings. Documents must be received by the IRB at least 30 days before the expiry date. This is for the purpose of facilitating the review process. Any documents received less than 30 days before expiry will be labelled "late submissions" and will incur a penalty.
- Every 6 (six) months a progress report form supplied by ERES IRB must be filled in and submitted to us.
- A reprint of this letter shall be done at a fee.

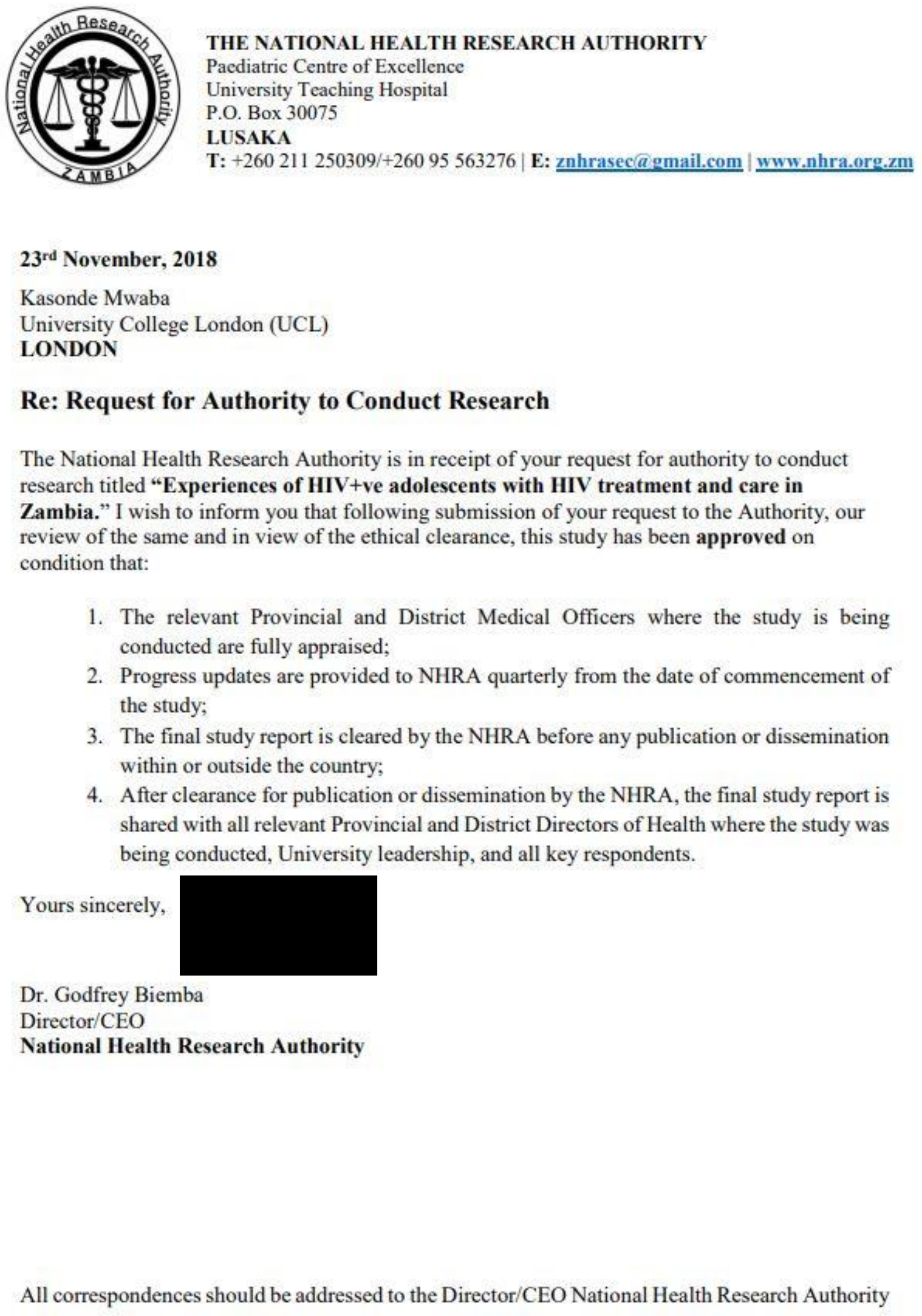
Should you have any questions regarding anything indicated in this letter, please do not hesitate to get in touch with us at the above indicated address.

On behalf of ERES Converge IRB, we would like to wish you all the success as you carry out your study.

Yours faithfully,
ERES CONVERGE IRB

[redacted]

Prof. E. Munalula-Nkandu
BSc (Hons), MSc, MA Bioethics, PgD R/Ethics, PhD
CHAIRPERSON



THE NATIONAL HEALTH RESEARCH AUTHORITY
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23rd November, 2018

Kasonde Mwaba
University College London (UCL)
LONDON

Re: Request for Authority to Conduct Research

The National Health Research Authority is in receipt of your request for authority to conduct research titled **"Experiences of HIV+ve adolescents with HIV treatment and care in Zambia."** I wish to inform you that following submission of your request to the Authority, our review of the same and in view of the ethical clearance, this study has been **approved** on condition that:

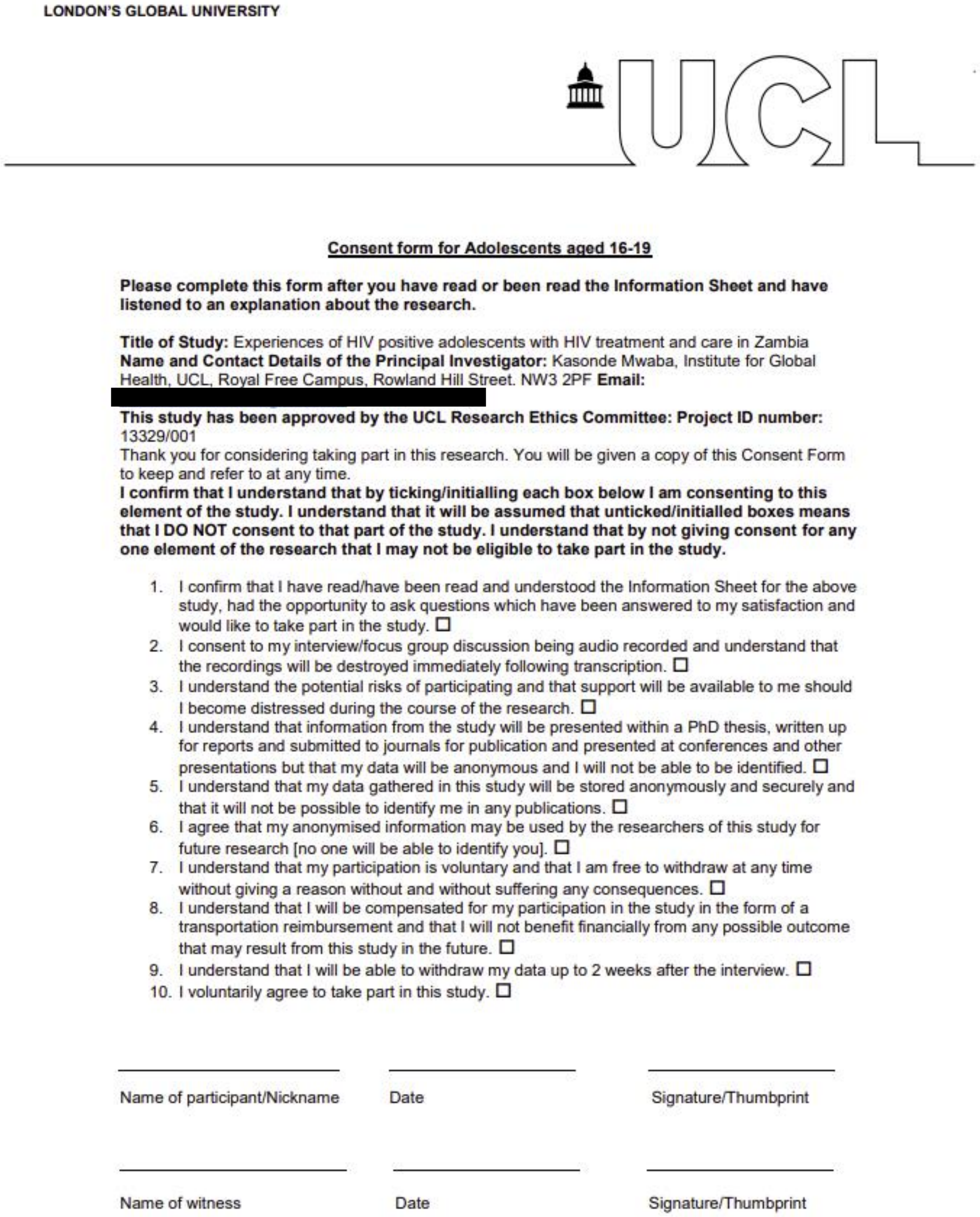
1. The relevant Provincial and District Medical Officers where the study is being conducted are fully appraised;
2. Progress updates are provided to NHRA quarterly from the date of commencement of the study;
3. The final study report is cleared by the NHRA before any publication or dissemination within or outside the country;
4. After clearance for publication or dissemination by the NHRA, the final study report is shared with all relevant Provincial and District Directors of Health where the study was being conducted, University leadership, and all key respondents.

Yours sincerely, [redacted]

Dr. Godfrey Biemba
Director/CEO
National Health Research Authority

All correspondences should be addressed to the Director/CEO National Health Research Authority

Appendix B : Adolescent consent form



LONDON'S GLOBAL UNIVERSITY

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Consent form for Adolescents aged 16-19

Please complete this form after you have read or been read the Information Sheet and have listened to an explanation about the research.

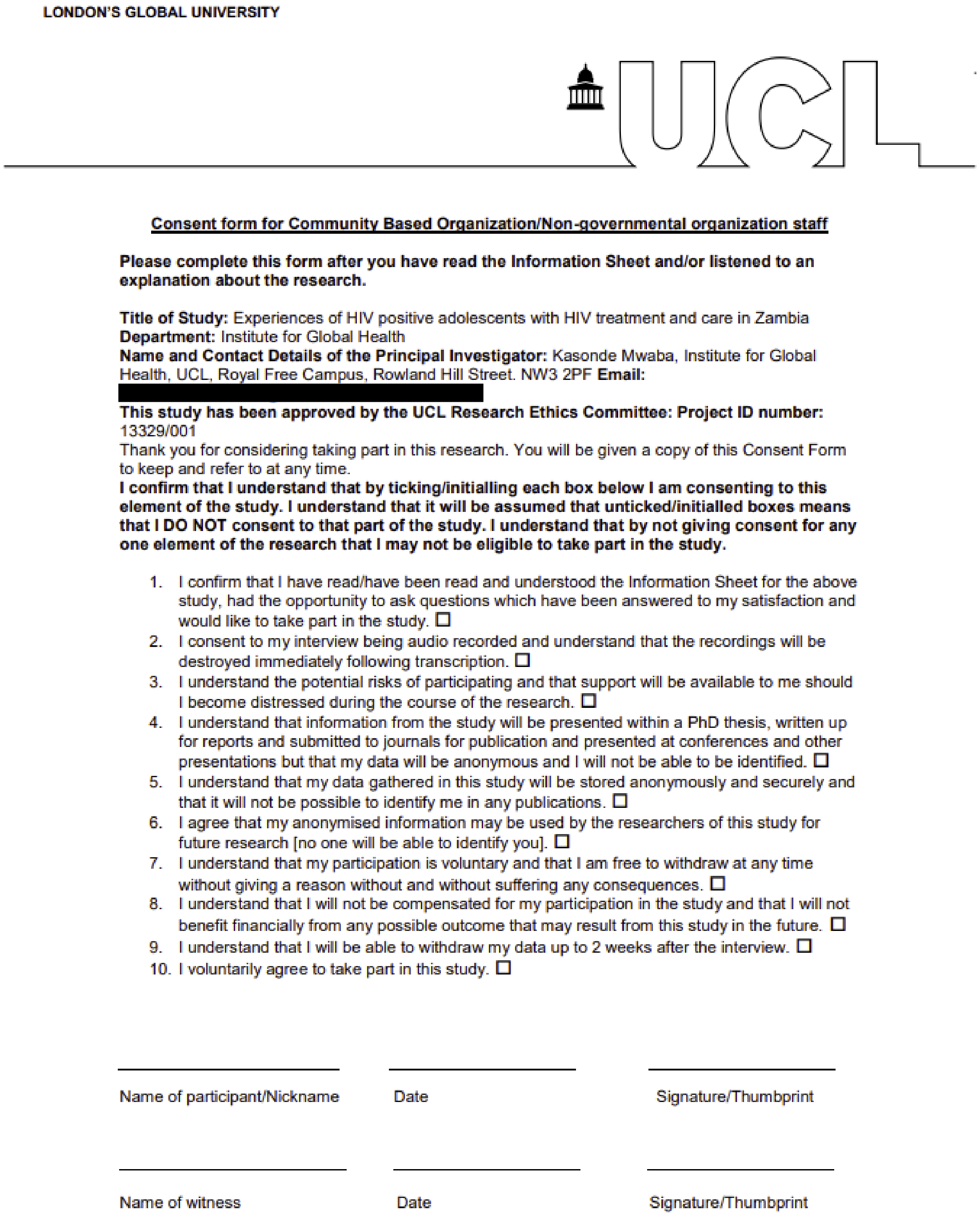
Title of Study: Experiences of HIV positive adolescents with HIV treatment and care in Zambia
Name and Contact Details of the Principal Investigator: Kasonde Mwaba, Institute for Global Health, UCL, Royal Free Campus, Rowland Hill Street. NW3 2PF **Email:** [redacted]

This study has been approved by the UCL Research Ethics Committee: Project ID number: 13329/001
Thank you for considering taking part in this research. You will be given a copy of this Consent Form to keep and refer to at any time.
I confirm that I understand that by ticking/initialling each box below I am consenting to this element of the study. I understand that it will be assumed that unticked/initialled boxes means that I DO NOT consent to that part of the study. I understand that by not giving consent for any one element of the research that I may not be eligible to take part in the study.

1. I confirm that I have read/have been read and understood the Information Sheet for the above study, had the opportunity to ask questions which have been answered to my satisfaction and would like to take part in the study. ☐
2. I consent to my interview/focus group discussion being audio recorded and understand that the recordings will be destroyed immediately following transcription. ☐
3. I understand the potential risks of participating and that support will be available to me should I become distressed during the course of the research. ☐
4. I understand that information from the study will be presented within a PhD thesis, written up for reports and submitted to journals for publication and presented at conferences and other presentations but that my data will be anonymous and I will not be able to be identified. ☐
5. I understand that my data gathered in this study will be stored anonymously and securely and that it will not be possible to identify me in any publications. ☐
6. I agree that my anonymised information may be used by the researchers of this study for future research [no one will be able to identify you]. ☐
7. I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason without and without suffering any consequences. ☐
8. I understand that I will be compensated for my participation in the study in the form of a transportation reimbursement and that I will not benefit financially from any possible outcome that may result from this study in the future. ☐
9. I understand that I will be able to withdraw my data up to 2 weeks after the interview. ☐
10. I voluntarily agree to take part in this study. ☐

Name of participant/Nickname	Date	Signature/Thumbprint
Name of witness	Date	Signature/Thumbprint

Appendix C: Health Service Provider consent forms



LONDON'S GLOBAL UNIVERSITY

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Consent form for Community Based Organization/Non-governmental organization staff

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

Title of Study: Experiences of HIV positive adolescents with HIV treatment and care in Zambia
Department: Institute for Global Health
Name and Contact Details of the Principal Investigator: Kasonde Mwaba, Institute for Global Health, UCL, Royal Free Campus, Rowland Hill Street. NW3 2PF **Email:**
[redacted]
This study has been approved by the UCL Research Ethics Committee: Project ID number: 13329/001
Thank you for considering taking part in this research. You will be given a copy of this Consent Form to keep and refer to at any time.
I confirm that I understand that by ticking/initialling each box below I am consenting to this element of the study. I understand that it will be assumed that unticked/initialled boxes means that I DO NOT consent to that part of the study. I understand that by not giving consent for any one element of the research that I may not be eligible to take part in the study.

1. I confirm that I have read/have been read and understood the Information Sheet for the above study, had the opportunity to ask questions which have been answered to my satisfaction and would like to take part in the study. ☐
2. I consent to my interview being audio recorded and understand that the recordings will be destroyed immediately following transcription. ☐
3. I understand the potential risks of participating and that support will be available to me should I become distressed during the course of the research. ☐
4. I understand that information from the study will be presented within a PhD thesis, written up for reports and submitted to journals for publication and presented at conferences and other presentations but that my data will be anonymous and I will not be able to be identified. ☐
5. I understand that my data gathered in this study will be stored anonymously and securely and that it will not be possible to identify me in any publications. ☐
6. I agree that my anonymised information may be used by the researchers of this study for future research [no one will be able to identify you]. ☐
7. I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason without and without suffering any consequences. ☐
8. I understand that I will not be compensated for my participation in the study and that I will not benefit financially from any possible outcome that may result from this study in the future. ☐
9. I understand that I will be able to withdraw my data up to 2 weeks after the interview. ☐
10. I voluntarily agree to take part in this study. ☐

Name of participant/Nickname	Date	Signature/Thumbprint
Name of witness	Date	Signature/Thumbprint

Consent form for health workers (doctors/nurses/community health workers/adherence support workers)

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

Title of Study: Experiences of HIV positive adolescents with HIV treatment and care in Zambia
Department: Institute for Global Health
Name and Contact Details of the Principal Investigator: Kasonde Mwaba, Institute for Global Health, UCL, Royal Free Campus, Rowland Hill Street. NW3 2PF **Email:**
[redacted]

This study has been approved by the UCL Research Ethics Committee: Project ID number: 13329/001
Thank you for considering taking part in this research. You will be given a copy of this Consent Form to keep and refer to at any time.
I confirm that I understand that by ticking/initialling each box below I am consenting to this element of the study. I understand that it will be assumed that unticked/initialled boxes means that I DO NOT consent to that part of the study. I understand that by not giving consent for any one element of the research that I may not be eligible to take part in the study.

1. I confirm that I have read/have been read and understood the Information Sheet for the above study, had the opportunity to ask questions which have been answered to my satisfaction and would like to take part in the study. ☐
2. I consent to my interview being audio recorded and understand that the recordings will be destroyed immediately following transcription. ☐
3. I understand the potential risks of participating and that support will be available to me should I become distressed during the course of the research. ☐
4. I understand that information from the study will be presented within a PhD thesis, written up for reports and submitted to journals for publication and presented at conferences and other presentations but that my data will be anonymous and I will not be able to be identified. ☐
5. I understand that my data gathered in this study will be stored anonymously and securely and that it will not be possible to identify me in any publications. ☐
6. I agree that my anonymised information may be used by the researchers of this study for future research [no one will be able to identify you]. ☐
7. I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason without and without suffering any consequences. ☐
8. I understand that I will not be compensated for my participation in the study and that I will not benefit financially from any possible outcome that may result from this study in the future. ☐
9. I understand that I will be able to withdraw my data up to 2 weeks after the interview. ☐
10. I voluntarily agree to take part in this study. ☐

Name of participant/Nickname	Date	Signature/Thumbprint
Name of witness	Date	Signature/Thumbprint

Appendix D: Adolescent Interview topic guide

Adolescent Interview Topic Guide

Hello! My name is _____ and I will be interviewing you today. Thank you for agreeing to take part in this study on the experiences of HIV positive adolescents with HIV treatment and care in Zambia. I will be asking you questions about your experience living as an HIV positive adolescent and your treatment experience. If any questions make you feel uncomfortable for any reason you do not have to answer them. You are also free to end the interview at any time without consequence. All your responses will be kept confidential and no one will be able to identify you from them.

Background

1) Can you tell me about yourself?
    a. Where are you from/born?
    b. How old are you?
    c. Can you tell me about your family?
        i. Marital status? Children?
    d. Are you currently in school? What grade are you in?
    e. What do you want to be when you grow up?

Experience and perceptions

2) Can you tell me about HIV?
    a. What does being HIV positive mean to you?
3) Can you describe your experience living with HIV?
    b. Can you tell me about how having HIV has affected your life? (examples-socially/physically/mentally, etc.)
4) From your experience, can you tell me about some of the factors driving the HIV epidemic in adolescents (individual/inter-personal/community/organization/nationally/regionally/globally, etc.)?

HIV Testing and linkage to care

5) Can you tell me about the first time you found out you had HIV?
    c. How old were you?
6) Can you describe what happened when you went for an HIV test?
7) Can you tell me about any difficulties or challenges you faced with getting an HIV test? (examples)
8) Can you tell me about anything or anyone that made it easier to get tested (facilitators/motivations)?
9) Can you tell me about the first time you saw a doctor (or nurse) after finding out you had HIV?
    a. What happened? What was it like? (Describe)
10) Can you tell me about any difficulties or challenges you faced when trying to see a doctor (or nurse)?
11) Can you tell me about anything or anyone that made it easier to go to the clinic and see a doctor (or nurse) for care after finding out you had HIV?
12) Can you tell me about how you coped or are coping with living with HIV?

13) Is there anything else you would like to share about your HIV testing experience or your experience seeing a doctor (or nurse)?

ART

14) Can you tell me about the time you started taking HIV medication?
    a. When did you begin? How long have you been taking them?
15) Can you tell me about any difficulties or challenges you face or faced with taking your medication as told (adhering to medication)?
16) Can you tell me about anything or anyone that makes it easier to take your medication as told? (facilitators/enablers)
17) Can you tell me about anything that might help support you take your medication as told/adhere to medication? (examples/interventions)?
18) Can you tell me about your experience during last year's cholera outbreak? How did it affect you? (access to clean water, sanitation, food, money…etc.)
    a. Did your behavior or thinking change? In what ways?
    b. Did it have any effect on your community? How people behaved?
    c. Did it have any influence on your wellbeing and engagement with treatment and care?

Clinic/Point of care

19) Can you tell me about the care you receive at the clinic and any services you use?
20) Can you tell me about anything or anyone at the clinic (or other point of care) that negatively or positively affects your treatment and care experience?

Disclosure

21) Can you tell me about who you have told about your HIV status and how it has influenced your experience living with HIV? (Who/when/why)
22) Can you describe what it is like living as an HIV positive youth in Lusaka?
23) Can you tell me about anything the government and other local organizations can do to better support HIV positive youth like yourself?

Other

Is there anything else you would like to share? Thank you so much for your participation.

Appendix E: Health service provider topic guides

<u>Health Care Workers Topic Guide</u>

Hello! My name is ___ and I will be interviewing you today. Thank you for agreeing to take part in this study on the experiences of HIV positive adolescents with HIV treatment and care in Zambia. I will be asking you questions about your experience caring for and treating HIV positive adolescents and your thoughts on their needs and challenges. If any questions make you feel uncomfortable for any reason you do not have to answer them. You are also free to end the interview at any time without any consequence. All your responses will be kept confidential and no one will be able to identify you from them.

<u>Participant ID:</u>

Background

1) Can you briefly tell me about yourself, your background and how you got into working with people living with HIV and AIDS?
2) How long have you worked with HIV positive adolescents?

Caring experience

3) Can you tell me about your experience caring for HIV+ adolescents?
    a. E.g. Thoughts? Concerns? Challenges?
4) Can you tell me about any differences you have noticed between caring for adults or children and caring for adolescents (aged 10-19)?

Adolescent experience

1) From your experience, can you tell me about some of the factors driving the HIV epidemic in adolescents (individual/inter-personal/community/organization/nationally/regionally/globally, etc.)?
2) Can you tell me about your thoughts on the experiences of HIV positive adolescents?
    a. How do you think having HIV affects the lives of adolescents (socially/ mentally/ physically, etc.)?

3) Adolescence is a period of growth in which individuals experience many developmental changes and challenges, can you tell me about how these experiences may influence treatment outcomes or experiences among adolescents?
4) From your experience can you tell me about some of the challenges adolescents face living with HIV?

HIV testing and linkage to care

5) Can you describe your clinic's policy on testing adolescents for HIV and linking them to treatment?
6) Can you tell me about the reasons adolescents choose to test for HIV?
7) Can you tell me about the barriers adolescents face to getting tested for HIV?
8) Can you tell me about some of the challenges adolescents face when coming to see a doctor (or nurse) after finding out they have HIV?
9) Can you tell me about what is being done or can be done to overcome these barriers and challenges?
10) Can you tell me about HIV testing during antenatal care?
    a. Can you tell me about the treatment or services pregnant adolescent girls receive?
    b. In an analysis of demographic health survey data I noticed that not all girls were offered a HIV test during antenatal care visits, why do you think that is?

ART and retention in care

11) Can you tell me about the challenges adolescents face with taking their medication as told?
12) Can you tell me about some of the reasons HIV positive adolescents drop out of care or poorly engage in care?
    a. What kind of challenges does your clinic experience?
13) In your experience, can you tell me about some of the facilitators to keeping adolescents in care?
14) Youth including adolescents have been found to have poorer treatment outcomes when compared with children and adults, can you tell me why this might be?
15) Can you tell me about how last year's cholera outbreak may have affected adolescents living with HIV? (access to clean water, sanitation, food, money…etc.)
    a. How it may have influenced their wellbeing and engagement in treatment and care?

Disclosure/Coping

16) From your experience, can you tell me about who adolescents share their HIV positive status with?
17) From your experience, can you describe the ways adolescents cope with living with HIV?

Needs

18) Can you tell me about the services offered to adolescents in your clinic? (adolescent support groups? Youth friendly services? Etc.)
19) Can you tell me about any unmet needs among HIV+ adolescents that you have noticed?
20) Can you describe what can be done by the government and its partners to better support HIV+ adolescents?

Other

Is there anything else you would like to share? Thank you so much for your participation.

Community-based and Non-Governmental Organization Topic Guide

Hello! My name is ___ and I will be interviewing you today. Thank you for agreeing to take part in this study on the experiences of HIV positive adolescents with HIV treatment and care in Zambia. I will be asking you questions about your experience working and caring for HIV positive adolescents and your thoughts on their needs and challenges. If any questions make you feel uncomfortable for any reason you do not have to answer them. You are also free to end the interview at any time without any consequence. All your responses will be kept confidential and no one will be able to identify you from them.

Participant ID:

Background

1) Can you briefly tell me about yourself, your background and how you got into working in HIV/AIDS?
2) How long have you been working with HIV positive adolescents?

Services and experience

3) Can you tell me about your personal experience supporting HIV+ adolescents?
4) Can you tell me about your organization and how you work to support people living with HIV specifically adolescents living with HIV in Zambia?

Adolescent experience

5) From your experience, can you tell me about some of the factors driving the HIV epidemic in adolescents (individual/inter-personal/community/organizational/national/regional/global, etc.)?
6) Can you tell me about your thoughts on the experiences of HIV positive adolescents?
    a. How do you think having HIV affects the lives of adolescents (socially/ mentally/ physically, etc.)?
7) Adolescence is a period of growth in which individuals experience many developmental changes and challenges, can you tell me about how these

experiences may influence treatment outcomes or experiences among adolescents?

8) From your experience can you tell me about some of the challenges adolescents face living with HIV?

HIV testing and Linkage to Care

9) Can you tell me about the barriers adolescents face to getting tested for HIV?
10) Can you tell me about some of the challenges adolescents face with seeing a doctor (or nurse) after finding out they are HIV+ (linked to care)?
11) Can you tell me about how your organization supports adolescents facing such challenges?

ART and Retention in Care

12) Can you tell me about some of the barriers HIV positive adolescents face with taking their medications as told?
13) In your experience, can you tell me about some of the facilitators that help adolescents take their medication as told?
14) Can you tell me about some of the reasons HIV positive adolescents drop out of care or poorly engage in care?
15) In your experience, can you tell me about some of the facilitators to keeping adolescents in care?
16) Youth including adolescents have been found to have poorer treatment outcomes when compared with children and adults, can you tell me why this might be?
17) Can you tell me about how last year’s cholera outbreak may have affected adolescents living with HIV? (access to clean water, sanitation, food, money…etc.)
    a. How it may have influenced their wellbeing and engagement in treatment and care?

Disclosure/Coping

18) From your experience, can you tell me about who adolescents share their HIV positive status with and why they might?
19) From your experience, can you describe the ways adolescents cope with living with HIV?

Needs

20) Can you tell me about some of the unmet needs of HIV+ adolescents?

21) Can you describe what can be done by the government and its partners to better support HIV+ adolescents?

Other

Is there anything else you would like to share?

Are you okay with your name and/or organization being named in the results of this study?

Thank you so much for your participation.

Appendix F: Example search strategy

Example PubMed strategy:

1 hiv/ (33329)

2 aids/ (15123)

3 human immunodeficiency virus.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (6079)

4 human immune deficiency virus.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (31)

5 HIV.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (50039)

6 acquired immunodeficiency syndrome.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (768)

7 acquired immune deficiency syndrome.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (3080)

8 AIDS.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (45552)

9 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 (69448)

10 self-disclosure/ (7058)

11 disclos*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (28231)

12 self-disclos*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (9613)

13 self disclos*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (9613)

14 10 or 11 or 12 or 13 (28231)

15 adolescent attitudes/ (19000)

16 child attitudes/ (7058)

17 adolescen*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (255636)

18 child*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (719327)

19 teen*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (22173)

20 young adult*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (46647)

21 youth*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (98178)

22 15 or 16 or 17 or 18 or 19 or 20 or 21 (905896)

23 developing countries/ (5180)

24 (low- and middle-income countr*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (2658)

25 (low- and middle-income nation*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (28)

26 (low* and middle incom* countr*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (2767)

27 (low* and middle incom* nation*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (28)

28 LMIC*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (667)

29 low* income countr*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (1332)

30 low* income nation*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (19)

31 low-income countr*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (1240)

32 low-income nation*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (16)

33 LIC*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (20125)

34 middle income countr*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (2895)

35 middle income nation*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (32)

36 middle-income countr*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (2895)

37 middle-income nation*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (32)

38 MIC*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (192822)

39 developing countr*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (10345)

40 developing nation*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (814)

41 under-developed countr*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (19)

42 under-developed nation*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (2)

43 under develop* countr*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (19)

44 under develop* nation*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (2)

45 underdeveloped countr*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (148)

46 underdeveloped nation*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (28)

47 less* developed countr*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (325)

48 less* developed nation*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (41)

49 less-developed countr*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (312)

50 less-developed nation*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (39)

51 least developed countr*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (62)

52 least developed nation*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (3)

53 least-developed countr*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (62)

54 least-developed nation*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (3)

55 third world countr*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (265)

56 third world nation*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (39)

57 third-world countr*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (265)

58 third-world nation*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (39)

59 (Afghanistan or Guinea-Bissau or Sierra Leone or Benin or Haiti or Somalia or Burkina Faso or Democratic People's Republic of Korea or South Sudan or Burundi or Liberia or Syrian Arab Republic or Central African Republic or Madagascar or Tajikistan or Chad or Malawi or Tanzania or Comoros or Mali or Togo or Democratic Republic of Congo or Mozambique or Uganda or Eritrea or Nepal or Republic of Yemen or Ethiopia or Niger or Zimbabwe or The Gambia or Rwanda or Guinea or Senegal).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (21530)

60 (Angola or Indonesia or Papua New Guinea or Bangladesh or Kenya or Philippines or Bhutan or Kiribati or Sao Tome or Principe or Bolivia or Kosovo or Solomon Islands or Cabo Verde or Cape Verde or Kyrgyz Republic or Kyrgyzstan or Sri Lanka or Cambodia or Lao People's Democratic Republic of Laos or Laos or Sudan).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (13296)

61 (Cameroon or Lesotho or Swaziland or Republic of the Congo or Mauritania or Timor-Leste or Cote d'Ivoire or Federated States of Micronesia or Tunisia or Djibouti or Moldova or Ukraine or Arab Republic of Egypt or Mongolia or Uzbekistan or El Salvador or Morocco or Vanuatu or Georgia or Myanmar or Vietnam or Ghana or Nicaragua or West Bank or Gaza or Honduras or Nigeria or Zambia or India or Pakistan).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (43186)

62 (Albania or Fiji or Namibia or Algeria or Gabon or Nauru or American Samoa or Grenada or Paraguay or Armenia or Guatemala or Peru or Azerbaijan or Guyana or Romania or Belarus or Islamic Republic of Iran or Russian Federation or Belize or Iraq or Samoa or Bosnia or Herzegovina or Jamaica or Serbia or

Botswana or Jordan or South Africa).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (27290)

63 (Brazil or Kazakhstan or St Lucia or Bulgaria or Lebanon or St Vincent or Grenadines or China or Libya or Suriname or Colombia or Macedonia or Thailand or Costa Rica or Malaysia or Tonga or Cuba or Maldives or Turkey or Dominica or Marshall Islands or Turkmenistan or Dominican Republic or Mauritius or Tuvalu or Equatorial Guinea or Mexico or Venezuela or Ecuador or Montenegro).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures] (68524)

64 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61 or 62 or 63 (371462)

65 9 and 14 and 22 and 64 (302)