



Faculty of Health and Medicine

**Perceptions and experiences of adolescents
living with HIV
in Malawi**

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I declare that this thesis is my own work and has not been submitted for the award of a higher degree elsewhere.

Abstract

Background: Malawi is among the countries with the highest HIV prevalence worldwide. Adolescents living with HIV face diverse challenges, such as stigma and discrimination, which influence their emotional wellbeing and long-term health, in addition to impacting HIV onward transmission. Furthermore, HIV education, especially the use of fear-based animation and visual aids, as well as the figurative language used for HIV, contributes to how young people perceive and respond to their HIV status, leading to poor health outcomes and decreased wellbeing.

Aim: The purpose of this study was to explore descriptions, perceptions, and representations of the HIV-virus among adolescents living with HIV in Malawi, as well as the role that the language used for HIV plays in creating this perception of HIV. It further aimed to examine the impact of these interpretations on their experiences and emotional wellbeing.

Methods: This qualitative study employed hermeneutic phenomenology and reflexive thematic analysis, and data were collected through semi-structured in-depth interviews, focus group discussions and drawings, which enhanced the elicitation of participants' HIV perceptions. Participants were sampled purposively and included 16 adolescents living with HIV, attending a peer support group in a hospital within Lilongwe, and five service providers working at this hospital.

Results: The adolescents imagined HIV as personified, harmful creature in their body with functional senses and gender identity. Those negative perceptions originated mainly from the local term used for HIV, HIV-related stigma and discrimination and HIV representations in hospital HIV books, which negatively impacted their emotional wellbeing. However, HIV peer support groups were identified as safe environments for learning about HIV and for debating HIV-related topics, especially in view of the usually required silence and secrecy to prevent stigma.

Discussion: The findings enhance the understanding of participants' lived experiences and perceptions of HIV, and thus may contribute to new methods of holistic health education, tailored for adolescents to improve their emotional wellbeing and attitudes towards HIV through context-specific programmes.

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List of Abbreviations and Acronyms

ABR	Arts-based research
ABYM	Adolescents and young men
AGYW	Adolescents and young women
AIDS	Acquired Immuno Deficiency Syndrome
ALHIV	Adolescents living with HIV
ART	Antiretroviral therapy
CASP	Critical Appraisal Skills Programme
CDC	Centers for Disease Control and Prevention
CINAHL	The Cumulative Index to Nursing and Allied Health Literature
EMBASE	Excerpta Medica dataBASE
et al.	et alia (Latin for “and others”)
FGD	Focus group discussion
GNI	Gross National Income
HBM	Health Belief Model
HDI	Human Development Index
HIV	Human Immunodeficiency Virus
IDI	In-depth interview
MEDLINE	Medical Literature Analysis and Retrieval System Online
MeSH	Medical Subject Heading
MMAT	Mixed Methods Appraisal Tool
MoH	Ministry of Health
NAC	National AIDS Commission
NSO	National Statistical Office
PhD	Doctor of Philosophy
PIS	Participant Information Sheet
PLHIV	People living with HIV
PRISMA-P	Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols
PROSPERO	The International Prospective Register of Systematic Reviews
PsycINFO	Psychological Information Database
SCT	Social Cognitive Theory
SEM	Socio-ecological model
SPIDER	Sample, Phenomenon of Interest, Design, Evaluation, and Research type (framework for framing research questions)
SSA	Sub-Saharan Africa
STI	Sexually Transmitted Infections

TA	Thematic analysis
U=U	Undetectable viral load equals untransmittable HIV infection
UNAIDS	Joint United Nations Programme on HIV/ AIDS
UNICEF	United Nations International Children's Emergency Fund
UNDP	United Nations Development Programme
U.S.	United States of America
WB	World Bank
WHO	World Health Organization

CHAPTER 1: INTRODUCTION

Malawi is among the countries with the highest Human Immunodeficiency Virus (HIV) prevalence among adolescents globally. These adolescents face numerous challenges, including HIV-related stigma and discrimination, as well as adherence to lifelong antiretroviral therapy (ART), which is crucial for them to stay healthy, but equally important for reducing the spread of HIV to the population. This thesis explores the lived experiences and perceptions of adolescents living with HIV (ALHIV) in Malawi. With the use of drawings, the participants were able to visualise and explain how they perceived the virus and the way it manifested in their bodies. Furthermore, the root of these perceptions and how these perceptions impact on their emotional wellbeing and health behaviour are discussed in order to inform HIV education approaches. This introductory chapter describes the researcher's motivation, the background to the research, the research justification, its aim, objectives and the research question. Additionally, an overview of the thesis structure will be presented.

1.1 Motivation of the researcher

The motivation to explore how ALHIV imagine and perceive the HIV-virus in their bodies resulted from encounters in my personal and professional life. Working as a clinical instructor at a Malawian nursing college and in health facilities showed me the reality of HIV and Acquired Immune Deficiency Syndrome (AIDS) in Malawi. Despite the availability of ART and HIV being documented as a chronic condition, personally witnessing HIV-related suffering and deaths of children and adults made me feel that quietly accepting these encounters would be unethical and inhumane. Therefore, I became actively engaged by volunteering at a local HIV peer support group for ALHIV. Furthermore, being part of a team producing HIV teaching videos for medical professionals to enhance the quality of HIV care facilitated a deeper insight into what it means to live with HIV in Malawi. The experiences I gained during an art therapy workshop with ALHIV taught me about misperceptions triggering fear and the effects of HIV-related stigma and discrimination on the identities of this vulnerable population. These projects motivated me to conduct a study, which actively sought to give voice to ALHIV in Malawi in order to understand their perceptions and where they stem from, which may help improve HIV education.

1.2 Background information

1.2.1 Malawi

With a total area of 118,480 km², the Republic of Malawi in sub-Saharan, South-Eastern Africa is a small landlocked country (WorldData, 2022), which is bordered by Mozambique, Tanzania and Zambia (Figure 1.1.).

Figure 1.1.

Map of Africa, including Malawi (Maps Malawi, 2022)



Malawi is a former British colony that attained independence in 1964; however, while English remains the official language, Chichewa, the national language, is widely spoken (Encyclopædia Britannica, 2022a). Its capital city Lilongwe in the Central region is Malawi's largest city, followed by Blantyre in the Southern region and Mzuzu in the Northern region (City Population, 2022). Among the diverse ethnic groupings, the Chewa are the largest group and the predominant religion is Christianity, followed by Islam and traditional faith (National Statistical Office [NSO], 2019). Furthermore, the majority of Malawians (84%) are living communally with their extended family members in rural areas of the country's three administrative regions and depend on farming (NSO, 2019). As in other collectivistic cultures, the families tend to be large, comprising five to six children, and serve as social support systems, for which men usually have principal authority and decision-making power (Tembo & Oltedal, 2015). Children from a young age are expected to take responsibilities, such as household chores or farming, and to show respect and obedience towards their caregivers, which incorporates non-refusal of caregiver requests (An et al., 2018). The population

comprises around 20 million people (Worldometer, 2022), of which 52% are aged below 18 years and only 4% above 65 years old (United Nations Population Fund, 2022).

After nearly six decades of independence, and with 70.3% of the population living below the poverty line, Malawi is still one of the poorest countries globally, which can be attributed, among other factors, to the low agricultural productivity and an increasing population (World Bank [WB], 2020; 2022a). The low life expectancy of only 64.3 years (United Nations Development Programme [UNDP], 2022a) and the high fertility rate of 4.06 (Statista, 2022) due to early pregnancies and low uptake of contraceptive methods, result in an annual population growth rate of 2.9% (NSO, 2019). This only adds to the burden on the country's limited resources, especially for health and social services. Thus, Malawi's Human Development Index (HDI), which evaluates countries' development in terms of education, gross national income (GNI) and life expectancy, ranks 171 out of 187 countries (UNDP, 2021). Table 1.1. below shows Malawi's progress regarding its human development from 1990 to 2019.

Table 1.1.

Trend in HDI for Malawi, 1990-2019 (UNDP, 2021)

Year	Life expectancy at birth	Expected years of schooling	Mean years of schooling	GNI per capita (2017 PPP\$)	HDI
1990	46.1	5.4	2.5	1405	0.303
1995	45.8	10.6	2.7	1287	0.363
2000	45.1	9.9	3.0	1422	0.362
2005	47.8	9.4	3.4	777	0.373
2010	55.6	10.3	4.3	959	0.437
2015	62.0	11.1	4.4	996	0.475
2016	62.7	10.9	4.5	1025	0.478
2017	63.3	11.0	4.5	1012	0.482
2018	63.8	11.0	4.6	1018	0.485
2019	64.3	11.2	4.7	1035	0.483

Notwithstanding the critical challenges Malawi is facing, Table 1.1. illustrates the progress in the areas of increased life expectancy and mean years of schooling, which reflects in an improved national literacy rate of 62% (UNDP, 2022a). Since 1994 primary education has been compulsory and free of charge (Encyclopædia Britannica, 2022b), but while 82% of Malawian children were enrolled into primary schools in 2018, only 61% (of which males are the majority) actually complete primary education (Education Policy Data Center, 2018) and progress to secondary school. The reasons for this include poverty and an inefficient education system, as well as an inadequate infrastructure (United Nations Children's Emergency Fund [UNICEF], 2022a).

Health inequities and inequalities in Malawi

Health inequities refer to distinctions between population groups regarding their health conditions, but is also concerned with differences in health resource distributions, resulting from “social conditions in which people are born, grow, live, work and age” (World Health Organization [WHO], 2018a) and leading to inequalities in health (Kawachi et al., 2002; Marmot & Allen, 2014). According to Marmot and Allen (2014), health inequalities could be reduced through enhancements in the social determinants of health, including education, living conditions, income and social support.

In Malawi, health inequalities largely stem from differences between the rich and poor populations with gendered educational statuses creating further disparities. This then impacts upon nutrition and uptake of health care, as well as life expectancy (Mulaga et al., 2022). Against this background and considering that 63% of Malawian children grow up in poverty (UNICEF Malawi, 2020), children aged under 5 years old of wealthier and well educated families were found to be less underweight, had a higher childhood vaccine coverage and a lower mortality rate. They were also more likely to receive medical attention for childhood illnesses, such as diarrhea or respiratory tract infections, compared to children of poor and less educated families (Mulaga et al., 2022; Yaya et al., 2016).

Poverty, as a cause and result of illness, may further explain Malawi’s high maternal and infant mortality rate, remaining more prevalent among deprived populations, due to their residence in rural areas, often a long distance from health facilities. As well as requiring transport, this means an over-reliance on births without the assistance of skilled birth attendants (Wong et al., 2020; Yaya et al., 2016). In addition, inadequate water and sanitation amenities, such as access to safe drinking water and toilets affect worse health outcomes among the poor (Cassivi et al., 2020). Moreover, inequalities exist in view of a higher disease burden and lower life expectancy among the poor and uneducated population (Arnold et al., 2020).

The role of gender pertaining to health inequalities in Malawi includes the fact that women are less likely to complete their school education compared to men, which limits not only their socioeconomic independency, but also makes them vulnerable to abuse and impedes their power in decision-making regarding health concerns (Adolfsson & Madsen, 2020). In addition, poverty and low educational levels, including sex education, contribute to the higher fertility rate, the lower contraceptive usage and, due to early sexual debut, to the high rate of teenage pregnancies in Malawi (An et al., 2018; Chirwa et al., 2019; Glynn et al., 2018). Also, knowledge of HIV transmission was evaluated higher in the wealthier population (Chirwa, 2020).

Malawi's health system

Malawi is facing the twofold burden of communicable diseases, including HIV, malaria, gastrointestinal and respiratory infections, as well as non-communicable diseases, such as diabetes and hypertension (Ministry of Health Malawi [MoH], 2017a). To respond to the population's needs accordingly, the health infrastructure in Malawi is largely funded through tax returns and donors (MoH, 2017b), and organised through governmental central hospitals, district hospitals and health centres, which offer main services, including HIV care, free of charge. In addition, services at private-for-profit and private-for-nonprofit health facilities are based on fees, commonly accessible to the wealthy population (Chansa et al., 2018). However, not all Malawians have equal access to free health services due to drug shortages and poor service quality (WB, 2017). This is compounded by the long distances to the health facilities, and associated transport costs (Peven et al., 2021).

1.2.2 HIV key information

Despite immense efforts by the Malawian government and numerous partner organisations, HIV still places a huge burden on Malawi's health system (United States Agency for International Development, 2022). HIV is a chronic condition that impairs the human immune system, leading to the inhibition of the body's protection against infections. AIDS is defined as "the most advanced phase of HIV infection", manifesting in the form of specific infections or cancer, that are progressing without treatment (WHO, 2022a). Initially people are typically asymptomatic and therefore unaware, but highly infectious at the early stages of HIV infection. Often, the symptoms of HIV infection, such as diarrhoea, fever and weight loss, are recognised when the HIV infection advances and thus, can further progress to opportunistic infections, including cancer, meningitis or tuberculosis (WHO, 2022a).

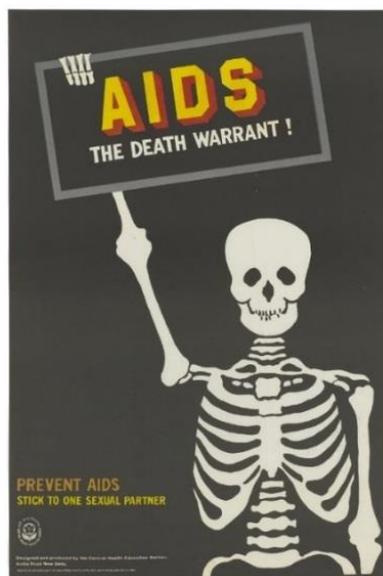
HIV is transmitted through body fluids, including blood, breast milk, seminal and vaginal secretions, as well as during pregnancy and delivery. Notably, HIV transmission can be prevented when people living with HIV (PLHIV) are on ART and virally suppressed (Knight et al., 2022). Hence, early treatment initiation and optimal adherence to ART is imperative for a healthy life of PLHIV, and at the same time crucial to prevent HIV onward transmission (Bezabhe et al., 2016). Optimal ART adherence, commonly evaluated by self report or pill count, is defined as the recommended behaviour of taking $\geq 95\%$ of ART in order to achieve viral suppression and avoid treatment failure (Paterson et al., 2000). Furthermore, to reduce the risk of HIV infection, the WHO recommends the use of condoms during sexual contact, the timely treatment of sexually transmitted infections (STI) and the avoidance of using contaminated needles in hospital settings or when injecting drugs (WHO, 2022a).

Since 2014, the Joint United Nations Programme on AIDS (UNAIDS) supports an improved and coordinated approach to manage the HIV epidemic. As part of the Sustainable Development Goals, this includes improving the HIV testing, treatment and viral suppression rates through the 90-90-90 targets by 2020 and 95-95-95 targets by 2030 with the aim of ending the AIDS epidemic by 2030 (UNAIDS, 2014). This translates to 90%/95% of PLHIV being aware of their HIV status, 90%/95% of PLHIV who know their HIV status should be on ART, and 90%/95% of PLHIV on ART should achieve viral suppression. The WHO (2021) defines HIV viral suppression as ≤ 200 copies/ml, whereas virologic failure refers to a viral load of ≥ 1000 copies/ml.

According to the WHO (2022a), the estimated number of deaths due to HIV and AIDS reached 40.1 million, but to date there is still no cure or vaccine for HIV. Scientific evidence suggests that ART plays a crucial part in controlling the HIV epidemic through reduced morbidity and mortality in PLHIV (Ford et al., 2018; Montaner et al., 2006), but also regarding HIV onward transmission via the “Treatment as Prevention” strategy (Mayer et al., 2013; Tanser et al., 2013). Aiming to prevent more HIV infections and reduce HIV-related deaths by 2030, the WHO initiated the “Test and Treat” recommendations in 2016, making all PLHIV eligible to start lifelong ART once tested HIV-positive (WHO, 2019a). Importantly, ART has drastically changed HIV from a “killer disease” to a chronic, manageable condition. This change is also reflected in public health HIV communication, such as from India used in 1990:

Figure 1.2.

“An AIDS prevention advertisement by the Central Health Education Bureau in New Delhi, 1990.” (Mosaic, 2014)



In comparison to the terrifying message above, a modern HIV public health message for the World AIDS Day in 2016 on a poster in Germany can be seen at Figure 1.3.

Figure 1.3.

“There is medicine against HIV, but not for dumb talk.” (Progress Werbung, 2018)

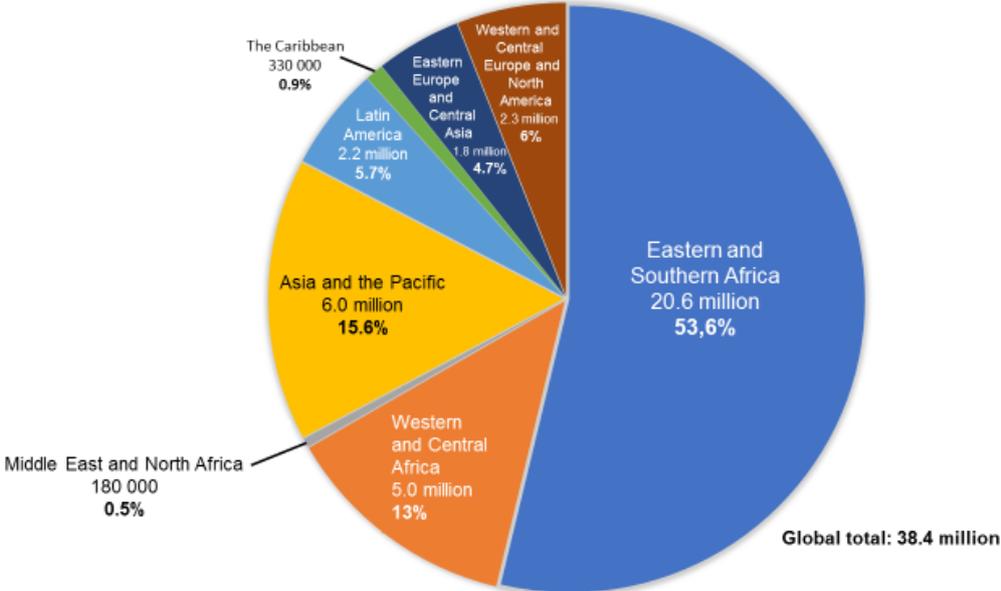


This transformation in HIV communication was only feasible through ART and clearly demonstrates that ‘living positively with HIV, but without discrimination’ are important drivers of managing the epidemic. However, since the roll-out of “Test and Treat”, substantial progress has been noted, particularly concerning the decreasing HIV incidence (Girum et al., 2018). Yet, despite positive achievements, some countries seem not to meet the UNAIDS targets by 2030, as in 2021 worldwide only 75% of PLHIV accessed ART, 650,000 HIV-related deaths were recorded and 1.5 million people were newly infected with HIV, particularly in sub-Saharan Africa (SSA) (UNAIDS, 2022). Therefore, according to UNAIDS (2020a), an effective public health response to HIV entails a skilled and adequate health workforce, the availability of sufficient HIV testing kits and ART, as well as campaigns against HIV-related stigma and discrimination.

1.2.3 HIV in sub-Saharan Africa

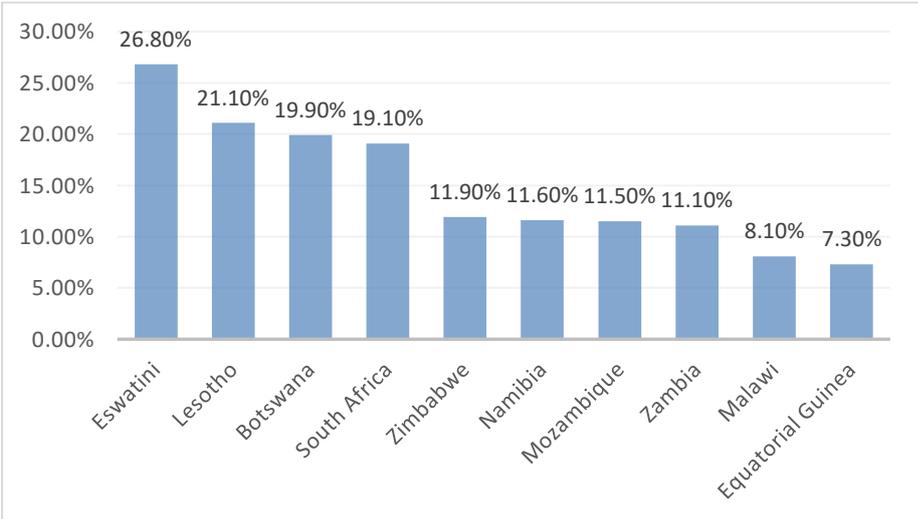
Despite evidence that the global HIV prevalence is reducing, the prevalence in countries of the SSA region is still high. From 38.4 million PLHIV worldwide, over 66% reside in the African region (UNAIDS, 2022). Figure 1.4. clearly shows the unequal distribution of global HIV prevalence.

Figure 1.4.
Regional HIV data - 2021 (UNAIDS, 2022)



In SSA HIV is regarded as a generalised epidemic, affecting the general population with specific groups, such as sex workers or injecting drug users, being at higher risk of contracting and transmitting HIV (Blower & Okano, 2019). Sexual intercourse is the primary mode of HIV transmission, followed by HIV mother-to-child transmission (Kharsany & Karim, 2016). Of the ten countries with the highest HIV prevalence globally, all are situated in SSA (Figure 1.5.), with the highest figure of 26.8% in Eswatini.

Figure 1.5.
HIV prevalence rates by country - 2020 (World Population Review, 2022)



Possible reasons for the higher HIV prevalence in SSA include poverty, early sexual activity, illiteracy, polygamy, gender-based violence, gender inequality, a high STI prevalence, as well as a lack of qualified health personnel and resources (Allinder & Fleischman, 2019; Inungu & Karl, 2006; Nyindo, 2005). Furthermore, cultural practices, HIV-related stigma and discrimination, the late introduction of HIV education campaigns (Barrett, 2007) - but also the delayed roll-out of HIV testing and ART - have all played their part in fuelling the HIV epidemic in SSA (Hoen et al., 2011).

Since countries within SSA have implemented the “Test and Treat” strategy, the number of people initiated on ART has significantly increased, which consequently formed a decline in the HIV-related mortality rate (WHO, 2019b). Nevertheless, not all PLHIV access treatment due to a range of barriers, including the fear of stigma, negative attitudes by healthcare personnel, insufficient knowledge about ART, fear of ART side effects and long distances to hospitals (Cataldo et al., 2017; Katz & Bangsberg, 2016). Notwithstanding the global efforts to end HIV by 2030, in order to achieve this goal, more endeavours are required. In particular, this relates to reducing HIV-related stigma, as this shows to be one of the biggest obstacles for people to get tested for HIV, as well as for accessing and adhering to treatment (Nyblade et al., 2021). However, this implies the need for ending the inequalities that exist regarding gender, health statuses and populations in order to leave no one behind (Kavanagh & Nygren-Krug, 2021; UNDP, 2022b). Due to the reality that the HIV incidence in SSA among adolescents aged 15-19 years is much higher in girls compared to boys, and 63% of recent infections with HIV in SSA were passed on by the female population, focus areas now need to include female empowerment strategies, targeting the educational sector and improved access to treatment and care (UNAIDS, 2022).

Public health education in SSA often carries fear-based messages, such as “AIDS kills” and scary images, which further stigmatises this marginalised population and fails to reflect the modern reality of living with HIV and adhering to ART (Asogwa & Esimokha, 2018; Green & Witte, 2006; Madiba, 2013). While some health educators judge these HIV prevention messages as being effective for behaviour change (Kaleeba, 2000; Terblanche-Smit & Terblanche, 2010; Witte & Allen, 2000), others disagree, pointing out that with effective modern treatment these messages are no longer appropriate. They propose the use of evidence-informed, culturally appropriate approaches (Albarracín et al., 2005; Asogwa & Esimokha, 2018; Fairchild et al., 2018). Moreover, the language used for HIV in SSA is often figurative and metaphorical. Translations of terms used for HIV in SSA include “bad insect” in the Democratic Republic of Congo (Mupenda et al., 2014), “monster” in Tanzania (Uys et al., 2005), “beast” or “zombie” in Kenya (Magonya, 2012) and “small beast” or “small animal” in

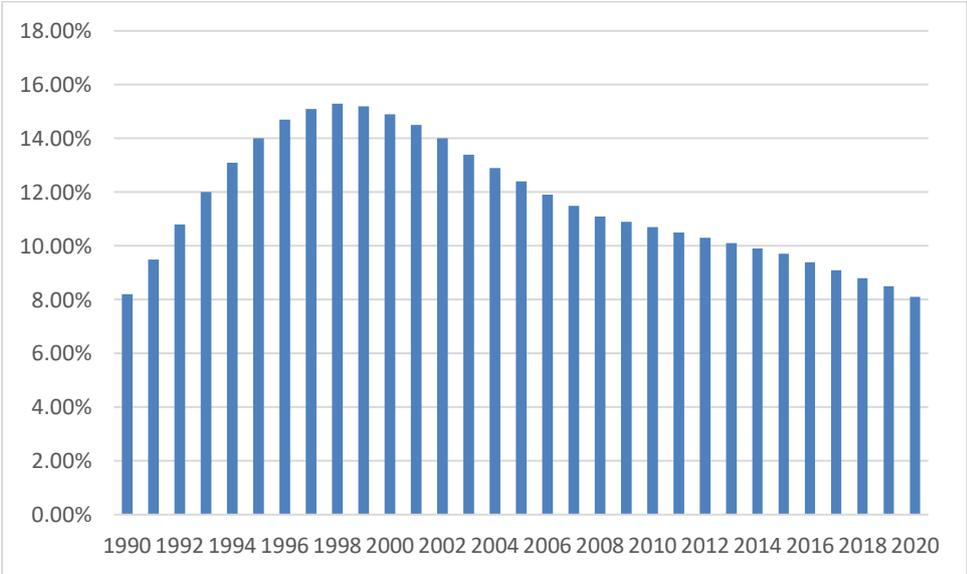
Malawi (Conroy et al., 2013; Lwanda, 2002). These terminologies, describing HIV as scary creatures, may contribute to misperceptions and stigma, but they may also act as barriers to engaging with HIV testing and treatment, and compromise HIV status disclosure (Uys et al., 2005).

1.2.4 HIV in Malawi

Malawi, as one of the ten countries with the highest HIV prevalence worldwide, identified its first HIV case in 1982 (McCormack et al., 2002), then eight years later, in 1990 an HIV prevalence of 8.2% was documented, while the highest prevalence of 15.3% appeared in 1998 as highlighted in Figure 1.6. Since then, attributed to the growing availability of ART, the rate is continuously decreasing, with the latest HIV prevalence of 8.1% in 2020 (WB, 2022b).

Figure 1.6.

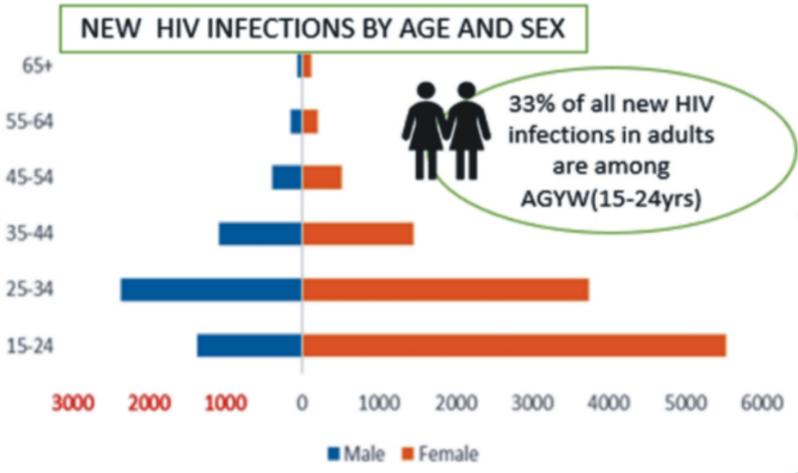
Prevalence of HIV, total (% of population ages 15-49): Malawi 1990 - 2020 (WB, 2022b)



Currently, the total number of PLHIV in Malawi stands at over one million (National AIDS Commission [NAC], 2020), with a higher prevalence in urban areas and in the female population, with especially the younger age group (15-24 years) being disproportionately affected (10.8%) compared to males (6.4%) (NAC, 2022a). Figure 1.7. shows that adolescent girls and young women (AGYW) account for 33% of new infections with HIV (NAC, 2022b).

Figure 1.7.

New HIV infections by age and sex in Malawi (NAC, 2022b)



It is estimated that to date 1.2 million people have died due to HIV in Malawi, however, since the roll-out of ART free of charge in 2004, the HIV-related mortality rate is declining (NAC, 2020). Nevertheless, the largest gap regarding ART coverage was found among AGYW and adolescents and young men (ABYM) living with HIV in Malawi (NAC, 2022b). This is concerning, especially in view of the adolescents' early age of first sexual encounter (mean: 16.8 years) and their practice of concurrent intimate relationships, which further fosters the HIV epidemic (Muriaas et al., 2019).

Nevertheless, Malawi is still on its way to achieving the UNAIDS 95-95-95 targets with current results showing that 91% of the population is aware of their HIV status, 94% of PLHIV in Malawi are on ART and 94% of those on ART presented with a suppressed viral load value (UNAIDS, 2020a). Notwithstanding the national and international efforts, the HIV epidemic further impacts Malawi's socio-economic development negatively. Therefore, the national response to the HIV epidemic, coordinated by NAC, is crucial for effectively implementing planned strategies. In 2016, Malawi signed the UNAIDS targets to end the HIV epidemic by 2030, and subsequently commendably scaled up ART through the "Test and Treat" policy (NAC, 2022a). Moreover, responding to the country's past successes in their control of HIV, Malawi's current National Strategic Plan for HIV and AIDS 2020-2025 serves as a road map for a multidisciplinary strategy (NAC, 2020). Included approaches entail evidence-based programmes to reduce the HIV transmission rate.

Therefore, Malawi continues focusing on increased condom usage and voluntary medical male circumcision. This decreases the risk for males getting infected by 60% (WHO, 2018b), enhances early identification and treatment of STIs and tuberculosis, as well as pre-exposure prophylaxis - referred to prophylactic ART intake by HIV-negative key and vulnerable

populations, such as sex workers, as it reduces the risk of contracting HIV (WHO, 2022b). Also the elimination of HIV mother-to-child transmission remains on the agenda of the national response plan. In addition, the present strategy aims to increase the focus on key populations, such as adolescent girls and young women, because cultural customs, such as initiation rituals and gender inequalities promote a low school enrolment rate, risky sexual contact, early childbearing, gender-based violence and inadequate access to sexual and reproductive health services (NAC, 2020). Hence, the concrete objectives for AGYW include a decrease of 22% in new HIV infections, an increased HIV testing rate of 90% and 90% condom use rate in the AGYW and ABYM population - as well as 75% of AGYW to demonstrate 75% knowledge on HIV (NAC, 2020).

To accomplish those objectives, besides a well designed and coordinated approach, the government of Malawi is aware that an improved health services infrastructure and sufficient skilled health personnel is crucial to turn this plan into action (NAC, 2020). Moreover, to respond to the needs of the adolescent population, including ALHIV, interventions require the inclusion of culturally appropriate, youth-friendly health service strategies (NAC, 2022b).

1.3 Adolescents living with HIV in Malawi

The number of ALHIV, aged 10-19 years, is estimated to be 1.74 million worldwide, with 60% living in Eastern and Southern Africa (UNICEF, 2021). Furthermore, the HIV-related mortality rate among ALHIV has increased, reaching a crescendo as the leading cause of death among this group in SSA (WHO, 2019a). Moreover, although the HIV testing rates among adolescents are very low with only 25% of female and 17% of male adolescents aged 15-19 years tested for HIV in Eastern and Southern Africa, girls aged 10-19 years contribute worldwide to 75% of new HIV infections among adolescents and in SSA they are showing a two to three times higher HIV susceptibility compared to their male counterparts (UNICEF, 2022b). Thus, accurate knowledge on HIV is essential for prevention, however, evidence shows that less than 50% of adolescents aged 15-19 years are able to correctly make statements regarding HIV prevention methods, related misconceptions and the physical invisibility of HIV in PLHIV (UNICEF, 2022b).

Malawi falls under the ten countries with the highest HIV prevalence among adolescents (UNAIDS, 2020b) with the main mode of transmission being either through mother-to-child transmission or sexual intercourse (Williams et al., 2017). Considering that 50% of Malawi's population are aged below 18 years (UNICEF, 2018) and only one in five adolescents gets tested for HIV (UNAIDS, 2016), undiagnosed HIV further increases the probability of HIV onward transmission (Du et al., 2015). Since ART has transformed the prognosis of PLHIV by

achieving and maintaining an undetectable HIV viral load through ART adherence, the risk of onward HIV transmission can be eliminated (Eisinger et al., 2019). As such, ART plays a central role in the control of the HIV epidemic (Treatment as Prevention) (WHO, 2020a). Nevertheless, as still not all who need ART are served, more work is required regarding ART scaling up for children and ALHIV (WHO, 2022a).

For numerous ALHIV in SSA often vulnerable and challenged by their disadvantaged circumstances, adhering to ART is difficult (Adejumo et al., 2015; Lowenthal et al., 2014). Factors for inadequate ART adherence are multiple and complex. A systematic review identified barriers to optimal ART adherence, including forgetfulness, lack of support structures, insufficient age-appropriate health services, and also cultural and religious beliefs (Ammon et al., 2018). Additional challenges faced by ALHIV are attributed to economic difficulties (Ferry et al., 2022; Mutwa et al., 2013), being single or dual parent orphans, disclosure, depression (Kim et al., 2015; Mugo et al., 2021), as well as stigma and discrimination negatively influencing their health and wellbeing (Lowenthal et al., 2014; Zgambo et al., 2018). Disclosure refers to the process of telling a person about their HIV status. For ALHIV the WHO (2011) recommends a gradual exposure to HIV information, rather than a one time event, allowing ongoing discussions about the condition, which will be revealed once the ALHIV shows the maturity and stability to cope with an HIV diagnosis.

Adolescence, defined as the developmental phase of 10-19 years of age by the WHO (2020b), can further be divided into early adolescence (10-14 years) and late adolescence (15-19 years) (UNICEF, 2011). Recognising their physical, emotional, mental and social changes, this is a demanding period, progressing from being a child to an independent adult. For ALHIV this is especially true, as in addition to the developmental changes, they are required to accept their chronic and extremely stigmatised condition. This explains the high rate of failure for adherence to lifelong ART and retention in HIV care (Ndiaye et al., 2013).

HIV-related stigma and discrimination

Goffman (1963, p.3) describes stigma as “an attribute that is deeply discrediting within a particular social interaction”. HIV-related stigma fuels discrimination against PLHIV (UNAIDS, 2003) with the distinction between enacted stigma experienced from others, anticipated or expected stigma, and internalised stigma, referring to self-discrimination (Earnshaw & Chaudoir, 2009; Greeff et al., 2008). The platforms where ALHIV experience HIV-related stigma include the family (Mutumba et al., 2015), schools (Maughan-Brown & Spaul, 2014), communities (McHenry et al., 2017), and also health facilities (Famoroti et al., 2013). Due to fear of stigma and rejection, ALHIV avoid disclosing their HIV status to friends, intimate

relationships and even family members, placing themselves and intimate partners at risk (Nöstlinger et al., 2015). Furthermore, HIV-related stigma was found to be associated with poor mental health outcomes among ALHIV (Nabunya & Namuwonge, 2022). Particularly in regard to mental health, ALHIV's wellbeing as a combination of mental and physical health, needs frequent follow-ups in order to offer mental health services timely. Emotional wellbeing can be defined as "the presence of positive emotions and moods, the absence of negative emotions, satisfaction with life, fulfilment and positive functioning" (Centers for Disease Control and Prevention [CDC], 2018).

In addition, HIV-related stigma is a global concern, and originates from lack of education, fear and outdated misconceptions traced back to the early years of the HIV epidemic. This in turn causes shame, mental health challenges and contributes to health inequalities (Ending HIV, 2020). While mental health services in Malawi are limited (Betancourt et al., 2013), the prevalence of depression among Malawian ALHIV has been found to be 18.9% (Kim et al., 2014). Therefore, understanding and assistance from caregivers, the community and the health system is essential (MacPherson et al., 2015). In contrast to the positive and encouraging information ALHIV receive at the HIV peer support group meetings, more fear-based lessons about HIV are disseminated in schools, creating a knowledge barrier between ALHIV and their HIV-negative peers (Birungi et al., 2011). Recognising that school curricula are developed with the aim to raise awareness concerning HIV prevention, the need for pupils living with or affected by HIV in the classrooms are frequently neglected. For those, receiving contradictory messages about HIV, such as about "living positively with HIV" at the hospital and about "HIV as a killer" at schools, this causes not only confusion, but also creates a division between the HIV-positive and HIV-negative populations. With HIV as a presently manageable condition, HIV communication in general, including formal education in schools, would benefit from taking a wider perspective with careful examination of the impact those messages bear on HIV-related discrimination and stigma (Kimera et al., 2019; Peinado et al., 2020).

Also, visual aids used for HIV education in schools and health facilities may influence the perception of ALHIV. The use of animated films and booklets for adolescents in SSA has shown to improve knowledge regarding HIV (Ampath, 2015). While visual aids were found beneficial for explaining complex concepts, most animations make use of scary metaphors, such as monsters, to illustrate and explain HIV (Wong et al., 2006), which may create misconceptions (Mutonyi & Kendrick, 2011). Misinterpretations of visual education material has been demonstrated by a study involving South African adults, in which pictorial metaphors, such as the "HIV monster" were misunderstood (Carstens et al., 2006). Furthermore, cultural and religious norms, myths and misconceptions may shape the lived experiences, perceptions

and realities of ALHIV and the realities in which they live. Beliefs, such as “HIV as punishment from God”, “HIV is soiling people inside”, “HIV is spread through witchcraft” or “HIV can be cured by prayers” nourish the HIV-related stigmatisation and compromise the wellbeing and treatment adherence of ALHIV (Pantelic et al., 2018; Sano et al., 2016). Consequently it is important to note that adolescent wellbeing, in line with the Sustainable Development Goal 3 “To ensure healthy lives and promote wellbeing for all at all ages” (UNDP, 2022b), positively impacts health outcomes in adulthood (Layard et al., 2014).

1.4 Research justification

An art therapy workshop facilitated in 2016 in Southern Malawi to understand ART adherence and disclosure behaviour in ALHIV, found that the majority of participants had negative perceptions about the image of the HIV-virus (Picturing Health, 2018). The ALHIV drew monsters, snakes and ant-like creatures when asked to illustrate the virus, which might be associated with the “small beast”, the Malawian term used for HIV. However, showing an electron microscopic image of the HIV-virus during discussion brought very positive feedback. The ALHIV found the electron microscopic image much less frightening and some expressed relief when they saw it. Similarly, investigations into children’s views of cancer illuminated imagined monsters or unfriendly faces (Oakley et al., 1995). However, this was also the case with adults, whose drawings of their tumours depicted monsters (Van Leeuwen et al., 2015) and HIV has been portrayed as “gremlin” (Scott, 2009), illustrating illness perceptions.

Furthermore, the language used for certain conditions has an impact on illness perceptions, and as such, influences health behaviour (Jaspal & Nerlich, 2022; Stolberg, 2014; Weiss, 1997). Therefore, health beliefs, illness perceptions and terminologies used for certain conditions evidently impact health-seeking behaviour and treatment adherence, as well as mental and physical health outcomes (Abubakar et al., 2013). Using fear appeals in health communication to stir behaviour change has hitherto provoked controversial debates regarding its ethical appropriateness and usefulness since it shows limitations and frequently has been proven ineffective (Chapman, 2018; Moussaoui et al., 2021). One example would be sight of the graphic warning labels on cigarette packaging to encourage people to stop smoking (Strong et al., 2021). In addition, a study by Muthusamy et al. (2009), conducted with adult students in Namibia, concluded that using HIV-related fear appeals to an already anxious population, to be futile and inadvisable. This is consistent with the stance of Peters et al. (2018), who recommend the provision of information in view of coping with a condition, rather than threatening approaches. In contrast, a study of Bastien (2011) examining the perceptions regarding HIV prevention images among 15-24 year old Tanzanians with unknown HIV status, revealed their preference for fear-based approaches concerning effective HIV prevention.

However, as participants also mentioned the need for additional information within HIV communication strategies, the author recommended further exploration of using fear appeals in health education within the African context.

As fear strongly guides illness perceptions, numerous researchers recommend examining fear appeals in relation to their adverse psychological and ethical consequences (Bradley, 2011; Guttman & Salmon, 2004). With the growing number of ALHIV in SSA and therefore an increased prerequisite for age-appropriate attention and interventions, it is disputable whether the use of fear appeals in HIV communication for ALHIV facilitates acceptance of a person's condition and emotional wellbeing, and whether or not they are beneficial in effecting the desired treatment adherence.

Most research conducted on or with ALHIV focused on HIV incidence, prevalence and behaviour (Birdthistle et al., 2019; Karim & Baxter, 2019; Zgambo et al., 2018). However, the scientific evidence regarding HIV education and ALHIV's perceptions is more limited (Duflo et al., 2006). What is more, very few studies have investigated the lived experiences and perceptions of ALHIV in SSA linked to their imagination of the HIV-virus and their emotional wellbeing. Hence, a study, which gives ALHIV a voice and allows a creative form of expression through arts-based research methods to examine their lived experiences and perceptions regarding the HIV-virus - could indeed enhance a deeper understanding. Furthermore, this study aims to inform health education interventions which are more appropriately tailored for adolescents to improve their emotional wellbeing and attitudes towards HIV through context-specific programmes, which in turn may have an impact on the control of HIV and thus, on the development of Malawi.

1.5 Aim and objectives of the research

Aim

The aim of the research was to explore descriptions, perceptions and representations of the HIV-virus among adolescents living with HIV, and to examine the impact of these interpretations on their emotional wellbeing.

Objectives

The identified objectives to accomplish the aim of this research were to:

- (1) explore the language used for HIV, and the lived experiences and perceptions of ALHIV regarding the HIV-virus through conducting in-depth interviews;

- (2) investigate ALHIV's imagination of the HIV-virus through drawings and the impact of the visual products on their emotional wellbeing;
- (3) facilitate focus group discussions among ALHIV to discuss their visual products and their underlying meanings ascribed to these images;
- (4) elucidate on and contextualise the interpretations of service providers on ALHIV's visual products through a focus group discussion;
- (5) inform health education interventions that are tailored for adolescents to improve their emotional wellbeing and attitudes towards HIV through context-specific programmes.

1.6 Research question

In order to achieve the aim and objectives, the research question guiding the study was:

In what ways do adolescents living with HIV in Malawi imagine the HIV-virus and how do these images and the language used for HIV impact on their emotional wellbeing, perceptions and lived experiences?

1.7 Thesis structure

The thesis comprises six chapters, including **Chapter 1: Introduction.**

Chapter 2: Literature review

In this chapter existing literature concerning perceptions about HIV among ALHIV in SSA and knowledge gaps have been explored by the completion of a systematic literature review.

Chapter 3: Methodology

This chapter discusses the research philosophy, research design, research setting and population with eligibility criteria for participation, sample size and recruitment strategies adopted for the study. Furthermore, this chapter entails the data collection methods (repeat in-depth interviews and focus group discussions) with an emphasis on drawing as an arts-based research method in combination with phenomenology to allow ALHIV to express themselves. Additionally, the process of data collection is outlined and justified, followed by ethical considerations, data management, as well as trustworthiness and rigour of the research being described.

Chapter 4: Findings

In this chapter the data analysis and the three identified themes regarding ALHIV's perception of HIV (imagination of HIV, the language used for HIV, and understanding HIV) with their corresponding sub-themes are presented. Based on the phenomenological approach, the participants' perceptions and experiences with their meanings are elucidated with quotes and supported by insightful visual products.

Chapter 5: Discussion

This chapter is organised in view of the identified themes, which are, aligned to the theoretical framework, critically discussed and situated within the existing literature. Moreover, the implications of using an arts-based research method, as well as the strengths and limitations of the research are presented.

Chapter 6: Conclusion

In the last chapter a recapitulation of the thesis is provided in consideration of the research aim and the study's accomplishment of contributing to the existing knowledge base in this subject area. In addition, recommendations for future research and practice are discussed.

1.8 Conclusion

This introductory chapter has established the foundation for the thesis by presenting the researcher's motivation, the historical and contextual background essential for the research and the research justification, highlighting the need for research among the adolescent population living with HIV in Malawi. Furthermore, the aim, objectives and research question were outlined, followed by the presentation of the structure of the thesis. The subsequent chapter focuses on the literature review concerning HIV perceptions among ALHIV in SSA.

CHAPTER 2: LITERATURE REVIEW

Perceptions regarding HIV among adolescents living with HIV in sub-Saharan Africa: A Systematic Review

2.1 Introduction

The majority (81%) of ALHIV reside in SSA (UNAIDS, 2016). Despite the availability of ART, which changed the condition from a terminal to a chronic illness, ALHIV face numerous challenges, including adhering to ART and HIV-related stigma and discrimination, impeding their ability to cope with HIV (Adejumo et al., 2015). Furthermore, HIV education, especially the use of fear-based messages and visual aids, as well as the figurative language used for HIV, may be contributing to how adolescents perceive and respond to their HIV status, leading to poor health outcomes and decreased wellbeing (Asogwa & Esimokha, 2018).

Since illness perceptions among affected individuals and healthcare providers may differ significantly, the value of exploring and modifying negative and incorrect illness perceptions is recognised, considering their impact on coping strategies, health behaviour and outcomes (Leventhal et al., 2016). Illness perceptions refer to the representations or the understanding of a health condition being influenced by demographic, cultural, socio-economic and environmental factors (Broadbent et al., 2015). Individuals create an abstract construct generated by their beliefs, experiences, interpretation of the condition and the meaning associated with the health threat (Hagger & Orbell, 2003). Also, it is important to note that health information acquired at school, the media, community or health facilities shape illness perceptions (Husson et al., 2013). While positive illness perceptions have been associated with a faster recovery and emotional wellbeing (Fortenberry et al., 2014; Orbell et al., 2008), negative illness perceptions are linked to poor health outcomes and lower quality of life (Petrie et al., 2007). Furthermore, illness perceptions are essential determinants of behaviour, making research in this subject area vital to guide healthcare workers and policy makers in the development of appropriate and effective interventions, which respond to patients' needs and concurrently achieve behaviour change (Petrie et al., 2007). Consistently, several studies observed negative illness perceptions among ALHIV in SSA (Bernays et al., 2015; Doat et al., 2021; Mavhu et al., 2013; Mutumba et al., 2019; Thupayagale-Tshweneagae, 2010).

To date, no systematic review on HIV illness perceptions among ALHIV in SSA has been identified, and therefore, this systematic review has sought to address the question: "What are the perceptions regarding HIV among adolescents living with HIV in sub-Saharan Africa?"

2.2 Aim of the systematic review

This review was designed to obtain, appraise, analyse and summarise existing research on the perceptions of HIV among ALHIV in SSA. It attempted to identify knowledge gaps in this field, which the thesis endeavoured to address, and inform a wider discussion of how HIV perceptions among ALHIV might influence coping strategies and health outcomes. Reviewing the current evidence base on this topic at the beginning of the thesis was considered essential to support the researcher's justification of decisions regarding the research question, as well as the study's aim, objectives and design.

2.3 Literature review methodology

An initial scoping search was conducted prior to the review protocol development to collate an overview of available literature and research methodologies used. For this qualitative systematic review, the SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, Research type) tool was deemed suitable due to the inclusion of qualitative, quantitative and mixed-methods studies in the evidence synthesis (Cooke et al., 2012) and was utilised to outline the key concepts and formulate the review question (Table 2.1.).

Table 2.1.

SPIDER tool

(S) Sample	Adolescents living with HIV in sub-Saharan Africa
(PI) Phenomenon of Interest	HIV
(D) Design	Questionnaires, surveys, interviews, focus group discussions, arts-based qualitative research methods
(E) Evaluation	Experiences, perceptions
(R) Research type	Qualitative, quantitative and mixed-methods studies

The systematic review protocol was registered with the International Prospective Register of Systematic Reviews (PROSPERO): Registration number: CRD420.212.587.77. To demonstrate adequate quality of this systematic review, the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA-P) guidelines were adapted (Moher et al., 2015).

2.3.1 Inclusion and exclusion criteria for studies

Relevant studies were included according to the eligibility criteria presented in Table 2.2. Inclusion was limited to research published after 2004 based on the assumption that perceptions may have changed post ART roll-out in SSA (Deeks et al., 2013). Translation limitations meant only papers published in English and German were included. Consistent with the WHO (2003), adolescence was defined as the period between 10-19 years. Studies

involving participants whose ages in some cases extended beyond this age range were included if the data of participants aged 10-19 years were clearly distinguishable.

Table 2.2.

Inclusion and exclusion criteria

	Inclusion criteria	Exclusion criteria	Rationale
Research population/Sample	Adolescent population aged 10 to 19 years (as defined by the WHO, 2003)	Adults aged 20 years and above, as well as the paediatric population aged 9 years and below.	Adults aged 20 and above, and children aged 9 and below may perceive HIV different to the adolescent population.
	HIV acquired perinatally or during childhood or adolescence.	HIV-negative adolescents.	HIV-negative adolescents may perceive HIV differently compared to the affected population.
	Geographical region: Sub-Saharan Africa (as defined by the World Bank, 2021).	Geographical areas outside the sub-Saharan Africa region.	The global majority of ALHIV reside in the sub-Saharan Africa region.
Phenomenon of Interest	HIV illness perceptions.	Other health conditions.	The inclusion of other health conditions may present inconclusive results.
Research design	Qualitative, quantitative and mixed-methods studies.	NA	HIV illness perceptions were found to be investigated using all research designs.
Publication date	Articles published after 2004.	Studies published before 2004.	HIV illness perceptions may have changed after the roll-out of ART in that region (Deeks et al., 2013).
Language	Limited to English and German.	NA	Based on the reviewer's language competence.
Literature	Published, peer-reviewed full-text primary studies.	Systematic reviews and grey literature.	Systematic reviews are considered as secondary source and grey literature is not peer reviewed.

2.3.2 Search strategy

Main search terms were initially identified from key papers obtained during the scoping search: "Adolescents", "HIV", "Sub-Saharan Africa" and "Perceptions". To optimise the quality of the search strategy, alternative key terms were tested on two electronic databases (MEDLINE and PsycINFO) for verification. Alternative terms included synonyms and acronyms, medical subject headings (MeSH), singular and plural forms of terms, differences in spelling, as well as new and old terminologies. For obtaining different term forms, the wildcard (?) and the asterisk (*) were used. The search results were broadened and then narrowed by the use of

Boolean operators (OR, AND) (Appendix 1). The search terms were agreed in collaboration with the supervisory team. To incorporate a broad range of publications on the subject area, five electronic bibliographic databases and nine websites and journals were searched in March 2021 and updated in October 2022. Furthermore, five databases of ongoing research were explored to identify relevant research presently conducted, that may be included in the review at a later stage (Table 2.3.).

Table 2.3.

Databases and websites searches

Electronic bibliographic databases	Cumulative Index to Nursing and Allied Health Literature (CINAHL) Excerpta Medica dataBASE (EMBASE) Medical Literature Analysis and Retrieval System Online (MEDLINE) Psychological Information Database (PsycINFO) Web of Science
Journals and websites	BioMed Central Journal of AIDS and HIV Research Journal of the international AIDS society (JIAS) Journal of Social Aspects of HIV/AIDS (SAHARA-J) Centers for Disease Control and Prevention (CDC) Paediatric European Network for Treatment of Aids (PENTA) trials President's Emergency Plan for AIDS Relief (PEPFAR) United Nations International Children's Emergency Fund (UNICEF) World Health Organization: International Clinical Trials Registry
Databases of ongoing research	Medical Research Council UK MetaRegister of Controlled Trials National Institute of Health Research National Research Register Archive US National Library of Medicine

Finally, reference lists of 15 key publications and 15 expert consultations ensured no relevant studies were overlooked.

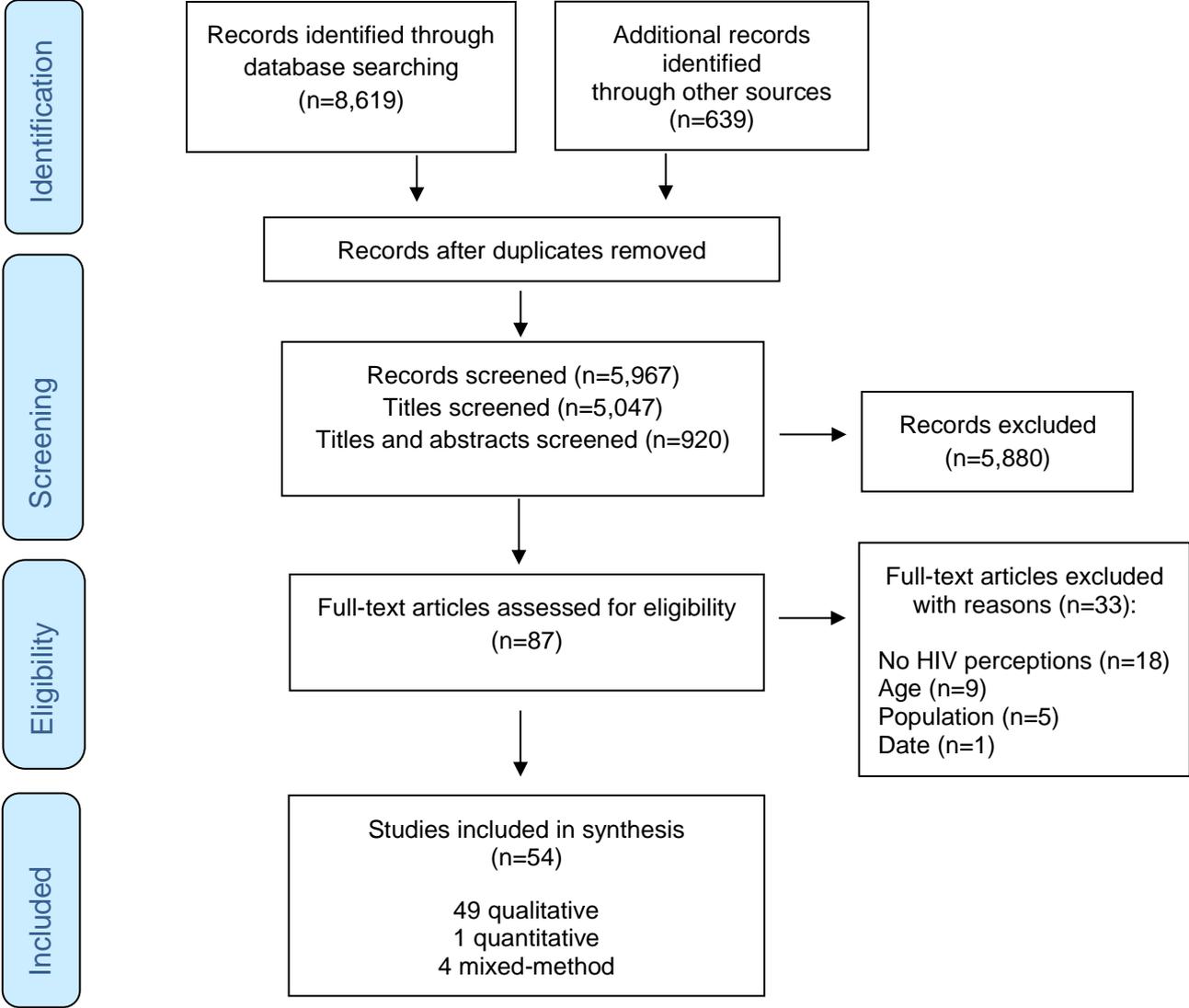
2.3.3 Selection of included studies

References of studies obtained during the search were recorded using the reference management software EndNote X7. Studies were de-duplicated and then underwent title screening followed by abstract screening in accordance with the predefined eligibility criteria. Publications deemed relevant or of uncertain relevance proceeded to full-text review. The reasons for exclusion of articles and the number of articles excluded at each stage were

documented and illustrated in a PRISMA flow diagram (Figure 2.1.). Included articles were recorded in a Microsoft Word® table.

Figure 2.1.

PRISMA flow diagram (Moher et al., 2009)



2.3.4 Critical appraisal of the literature

The critical appraisal of the methodological quality of included studies was performed using three different appraisal tools, chosen in accordance with the study design. The Critical Appraisal Skills Programme (CASP) checklist (2018) was employed for qualitative studies as this a recommended and widely used tool (Chenail, 2011). The Mixed-Methods Appraisal Tool (MMAT) Version 2011 (Pluye et al., 2011) was used to appraise the mixed-method studies as it is a validated tool developed for systematic reviews (Noyes et al., 2018). For quantitative

studies, the Checklist for Analytical Cross-Sectional Studies by the Joanna Briggs Institute (2017) was utilised as it is a well-structured, standardised tool (Aromataris & Pearson, 2014). Since there appears to be no consensus on superior appraisal tools for all research designs (Katrak et al., 2004), those appraisal tools were selected based on the researcher's familiarity with the tools. The findings of the quality appraisal were tabulated on a Microsoft Word® document (Appendices 2-4), reviewed with the supervisory team (inter-rater reliability) and are further discussed in the results and discussion section. No studies were excluded based on poor appraisal results, as their inclusion may allow recommendations on methodological improvements for future research.

2.4 Data extraction, synthesis and analysis

Key characteristics, relevant to the review aim, were extracted manually and recorded in a structured, tabulated form (Appendix 5). In consideration of both qualitative and quantitative studies included in this review, thematic synthesis (Thomas & Harden, 2008) was chosen to conduct data synthesis and analysis. While thematic synthesis is commonly used for qualitative systematic reviews, it is also suitable to integrate quantitative findings and facilitates the identification of common themes (Booth et al., 2016). Since narrative synthesis often lacks transparency (Popay et al., 2006) and framework synthesis (Brunton et al., 2020) is more suited to systematic reviews focused on theory development, thematic synthesis was found most appropriate for this literature review.

To permit a synergetic integration of qualitative and quantitative evidence, qualitative textual data were extracted from qualitative studies, and quantitative data was converted into qualitative evidence (Noyes et al., 2019). The three steps of thematic synthesis (coding of text, identification of descriptive and subsequent analytical themes) were followed with the identified themes organised and grouped as main themes and subthemes (Table 2.4.). Finally, links between the themes were reported. Data extraction, synthesis and analysis were independently conducted by the primary researcher, who regularly checked back with the supervisory team to ensure agreement with methodology and decision-making.

2.5 Results

Study characteristics

After 5,967 papers were title and abstract screened, 54 studies were included in this review (Figure 2.1.). All articles were published in English between 2010 and 2022. From the 54 included studies, 49 employed a qualitative study design, four a mixed-method design and one a quantitative cross-sectional design. Qualitative studies used predominantly in-depth interviews (IDI) as the data collection method (N=26); eleven studies used IDIs and focus

group discussions (FGD), and seven studies relied solely on FGDs. However, arts-based research methods, such as drawings (Pienaar & Visser, 2012), draw and tell (Van der Merwe & van der Merwe, 2020), photo voice (Kimera et al., 2020b) or photo elicitation (Mattes, 2014) and body mapping (Willis et al., 2018) were employed to enhance the understanding of ALHIV's illness perceptions. The studies were conducted in ten SSA countries, including South Africa (N=12), Uganda (N=8), Kenya (N=8), Zambia (N=6), Ghana (N=4), Tanzania (N=3), Zimbabwe (N=3), Botswana (N=3), Malawi (N=2) and Nigeria (N=1). Four studies conducted their research in two countries: Botswana and Tanzania (Midtbø et al., 2012), Kenya and Uganda (Loos et al., 2013), Uganda and Zimbabwe (Bernays et al., 2015), and Zambia and Kenya (Katirayi et al., 2021). Most of the studies used an urban research setting (N=28) followed by a rural-urban mix setting (N=12), whilst only three studies were conducted in a rural setting.

Characteristics of study participants

Sample sizes ranged from four to 119 in qualitative studies, and from 40 to 406 in quantitative studies. Of a total 2,390 research participants, 1,312 (55%) were female and 1,059 (45%) were male. Two studies, comprising each of six (Otieno & Obuya, 2019) and 13 participants (Adams & Crowley, 2021) did not mention participants' gender. Participants included in the 54 studies ranged from aged seven to 23 years. However, as specified in the eligibility criteria, only data of the age group 10-19 years was included in the data analysis. The most frequently involved age group was 15-19 years (N=9), followed by 12-19 years (N=8) and 10-19 years (N=6). While 15 studies limited inclusion to perinatally infected adolescents, most studies did not mention the route of HIV transmission (N=26). One study involved only ALHIV on second-line treatment after treatment failure (Lanyon et al., 2020) and one limited inclusion to ALHIV diagnosed with a major depressive disorder (Willis et al., 2018). Participants were extended beyond ALHIV in some studies, including caregivers, healthcare workers, HIV-negative adolescents (Abubakar et al., 2016) and adolescents whose HIV status was unknown (Katirayi et al., 2021).

Results of the critical appraisal

Overall, the methodological quality of the 54 included studies was evaluated as good (Appendices 2-4). However, it is important to note that only two (Adams & Crowley, 2021; Doat et al., 2021) out of 49 qualitative studies documented the researcher's influence on the research, 13 did not include the year the study was conducted, eight did not comment on study limitations, two did not report ethical approval for their studies (Mattes, 2014; Otieno & Obuya, 2019) and two did not comment on participants' gender (Adams & Crowley, 2021; Otieno & Obuya, 2019). These shortcomings may have impacted upon the quality and translatability of

the research findings. Qualifying study limitations enables readers to determine scientific rigour of the methodology, the robustness of conclusions made and to locate the findings in context (Ioannidis, 2007). Clarifying researchers' positionality permits recognition of potential influences on the research results (Holmes, 2020). Moreover, ethical approval of research is crucial for safeguarding the participants and ensuring principles of informed consent and confidentiality are upheld, specifically in view of ALHIV belonging to a vulnerable group of research participants (Bekker et al., 2014). The quality of the four mixed-method studies was evaluated as good. Nevertheless, research limitations were not presented in one study (Enimil et al., 2016), one article did not specify the year the study was conducted in (Enimil et al., 2016) and one did not comment on ethical approval for the research (Kaunda-Khangamwa et al., 2020). In the one quantitative study (Lawan et al., 2015) limitations were not discussed.

2.6 Thematic synthesis

The thematic synthesis aligns with the review question and the overall aim of this review, summarising HIV illness perceptions among ALHIV in SSA to inform the research design. This systematic literature review revealed four main themes and 14 subthemes (Table 2.4.), which are discussed in the subsequent sections.

Table 2.4.

Main themes and subthemes of literature review

Main themes	Subthemes	
Understanding HIV	HIV identity	Identity post HIV diagnosis HIV labels Feeling different
	HIV transmission	Limited understanding of HIV transmission Misconceptions around HIV transmission
	HIV duration	HIV as lifelong condition Unknown duration of HIV
Consequences of living with HIV	HIV-related stigma and discrimination Consequences for future aspirations and sexual decision-making No consequences	
HIV management and coping	Perceptions of ART Support structures Stigma Disclosure The power of knowledge Wider determinants of control	
Emotional HIV illness perceptions	Negative emotional illness perceptions	Emotions after disclosure Negative emotions regarding HIV in general Negative emotions regarding ART and HIV care Worries about the future Lack of information
	Positive emotional illness perceptions	Hope and optimism Acceptance

2.7 HIV illness perceptions

2.7.1 Understanding HIV

Subthemes identified under this main theme included “HIV identity”, “HIV transmission” and “HIV duration”.

HIV identity

Identity post HIV diagnosis

Perceptions concerning the nature of HIV ranged from descriptions of a “terrifying, deadly infection” (Maseko & Madiba, 2020; Mattes, 2014; Willis et al., 2018) to viewpoints, that HIV does not change a person’s identity (Crowley et al., 2019; Pienaar & Visser, 2012). However, the secret nature of the HIV diagnosis had a negative impact on their identity perception forcing ALHIV into a double life (Madiba & Mokgatle, 2016; Phuma-Ngaiyaye & Dartey, 2015). Several participants were able to identify HIV’s location in the body or blood (Appiah et al., 2019; Chory et al., 2021; Mattes, 2014), while others located it in the bones (Kunapareddy et al., 2014).

Knowledge deficits regarding the HIV transmission modes, for instance the belief that HIV is transmittable during “normal” interactions, such as playing or through sharing the toothbrush, were evident (Chory et al., 2021; Enimil et al., 2016; Willis et al., 2018). Poor understanding of modern evidence-based science around HIV transmission may detrimentally influence how an HIV diagnosis impacts a person’s perceived identity. Also, negative perceptions of HIV, rooted in stigma, were reported (Mutumba et al., 2015) and combative language was used to describe the challenges of living post HIV diagnosis (Pienaar & Visser, 2012). Petersen et al. (2010) concluded that ALHIV face enormous challenges of integrating HIV as a stigmatised condition into a healthy identity.

HIV labels

Studies discussed the labels for HIV, for PLHIV and ART, with most labels carrying negative connotations. Frequently HIV was labelled as dangerous (Dako-Gyeke et al., 2020; Kunapareddy et al., 2014); in one article participants termed HIV as “this modern disease”, and the virus was referred to as “small animals” translated from Swahili (Mattes, 2014). Furthermore, while HIV was portrayed as a demon (Mutumba et al., 2019), participants ambiguously described HIV as “this thing” (James et al., 2018). Since the awareness of HIV being a virus was reported in three studies (Appiah et al., 2019; Chory et al., 2021; Woollett et al., 2017), in one study HIV was referred to as a “curse” (Kunapareddy et al., 2014) and in seven studies participants stated not having received detailed information on the nature of HIV. PLHIV were diversely labelled as “HIV-positive”, “sick”, “victim”, “ghost” or as “those on medication” (Kimera et al., 2020a; Kimera et al., 2020b; Madiba & Josiah, 2019; Mutumba et

al., 2019). Labels used to refer to ART included “big drug” due to the pill containers’ large size (Kimera et al., 2020a).

Feeling different

ALHIV feeling different to their peers due to their HIV status, was reported in ten papers (Maseko & Madiba, 2020; Mattes, 2014). Their difference to HIV-negative peers was perceived in regard to their daily ART intake, their experiences with stigma and due to physical differences, such as stunting (Crowley et al., 2019; Pienaar & Visser, 2012). With the intention of avoiding stigma, ALHIV put considerable effort in appearing “normal” (Madiba & Mokgatle, 2016; Mupambireyi et al., 2014). In contrast, some participants pointed out that they feel “normal”, they take ART as part of their daily routine and compare HIV to an ordinary flu. Nonetheless, they still ensure that their HIV status is not disclosed (Adams & Crowley, 2021; Maseko & Madiba, 2020). However, accepting their HIV status was perceived as imperative to manage their condition, as by normalising HIV, knowing they are not the only ALHIV, they gained a positive self-concept which made them “equal” to others and detached them from the label of being “sick”. This in turn had a positive impact on their emotional wellbeing (Zanoni et al., 2020).

Findings illustrate the fact that the HIV identity is primarily constructed as negative among ALHIV, which is out of step with modern reality of living with HIV and likely influenced by pervasive HIV-related stigma. In addition, suboptimal awareness and knowledge of evidence-based science related to HIV further fuels these negative perceptions.

HIV transmission

ALHIV’s understanding regarding HIV transmission were discussed under two themes: “Limited understanding of HIV transmission” and “Misconceptions around HIV transmission”.

Limited understanding of HIV transmission

Fifteen articles identified a limited understanding of the transmission routes of HIV. Reasons for limited awareness included lack of open communication with caregivers and hesitancy to ask for this information (Adams & Crowley, 2021; Gitahi et al., 2020). In addition, participants questioned the validity of their diagnosis, in one case because they had never had sexual intercourse (Madiba & Mokgatle, 2016), and in another because they were the only sibling in the family living with HIV (Woollett et al., 2017).

Misconceptions around HIV transmission

Misconceptions regarding the transmission of HIV were discussed in seven studies. Misapprehensions included infection through spiritual routes, such as getting infected due to sinning and as punishment from God (Kimera et al., 2020a; Knizek et al., 2017; McHenry et al., 2017), infection through playing in the sand (Enimil et al., 2016), and ingestion of contaminated food (Mupambireyi et al., 2014). These findings demonstrate both a limited and, in some cases, incorrect understanding about HIV transmission. This poor knowledge foundation in turn may impact a person's illness perceptions.

HIV duration

ALHIV's perceived duration of HIV are discussed under the following two themes: "HIV as lifelong condition" and the "Unknown duration of HIV".

HIV as lifelong condition

The majority of participants understood HIV as a chronic condition, which was related to emotional distress (Hornschuh et al., 2014; Li et al., 2010; Okawa et al., 2017), particularly regarding the daily treatment requirements. Nevertheless, the knowledge about HIV as lifelong, but manageable reality, was perceived as supportive for HIV status acceptance and improved ART adherence (Dako-Gyeke et al., 2020).

Unknown duration of HIV

Several ALHIV indicated uncertainty about their condition's duration, which may be attributed to the lack of HIV-related communication (Denison et al., 2015; Gitahi et al., 2020). Additionally, some participants perceived HIV as a terminal condition (Lanyon et al., 2020; Petersen et al., 2010; Woollett et al., 2017), resulting in an early death and thus, causing emotional encumbrance (Doat et al., 2021; Van der Merwe & van der Merwe, 2020).

The knowledge of HIV as a lifelong condition represents both a cause of emotional distress, but may also trigger a shift towards acceptance of an HIV-positive status, facilitating self-care behaviour. Nevertheless, limited or inaccurate understanding about the timeline or progression of HIV infection may negatively influence ALHIV's HIV perceptions.

2.7.2 Consequences of living with HIV

Most ALHIV perceived HIV-related consequences as negative. Themes included "HIV-related stigma and discrimination", "Consequences for future aspirations and sexual decision-making" and "No consequences" due to HIV.

HIV-related stigma and discrimination

Stigma and discrimination, including internalised, anticipated and enacted stigma were the most frequently reported consequence among ALHIV in this review. While HIV-related stigma was discussed in general terms, others described experiencing stigma in specific social contexts, such as in the home environment, the community, at school and the hospital setting. In the home environment, discriminatory actions emanated from caregivers and siblings in the form of differential treatment, such as delegation of chores and separation of household items according to HIV status (Kaunda-Khangamwa et al., 2020). Additionally, tightly controlled ART intake (Otieno & Obuya, 2019) or feeling overprotected by caregivers were highlighted (Bernays et al., 2015). HIV-related stigma in the community comprised experiences of being bullied or avoidance (Ashaba et al., 2019; Callen et al., 2022), but also negative labelling or abandonment due to physical appearances, such as appearing underweight (Loos et al., 2013). At school, stigmatising attitudes of peers and teachers were described as differential treatment, such as avoidance or refusal to share items (Horns Schuh et al., 2014). Stigma experienced by peers and friends involved direct harassment and segregation from playing (Woollett et al., 2017). In some cases, HIV-related stigma drove ALHIV into a life of secrecy (James et al., 2018). This form of double life, often reinforced by caregivers (Bernays et al., 2015), necessitated ALHIV to lie about HIV and hide their ART use, which frequently led to poor ART adherence (Abubakar et al., 2016; Kawuma et al., 2014; Kunapareddy et al., 2014). Conversely, for some, the fear of discrimination improved ART adherence in order to suppress symptoms that might inadvertently reveal their HIV status (Mattes, 2014). However, social withdrawal due to HIV was characterised as reaction to disclosure (Gitahi et al., 2020; McHenry et al., 2017), protection against stigma (Dako-Gyeke et al., 2020), feeling different from peers (Willis et al., 2018; Zanoni et al., 2020), but also as strategy to avoid infecting others (Kimera et al., 2020b).

Consequences for future aspirations and sexual decision-making

HIV also led to perceived consequences on ALHIV's future aspirations, such as uncertainties regarding their professional career path (Katirayi et al., 2021; Mackworth-Young et al., 2021; Otieno & Obuya, 2019), but also on family building, which was particularly true for older ALHIV (Kaunda-Khangamwa et al., 2020; Li et al., 2010; Mburu et al., 2014b). Consequences on education, such as repetition of classes, changing or leaving school due to frequent illness and stigma, created feelings of frustration and sadness (Lawan et al., 2015; Mackworth-Young et al., 2017; Mburu et al., 2014b). Additionally, due to the limited privacy in boarding schools required for taking ART in concealment, ALHIV preferred day schools (Madiba & Josiah, 2019; Mutumba et al., 2019).

A further consequence of their HIV status was the impact HIV had on their sexual identity and relationship building. With the appeal for abstinence by caregivers, healthcare workers and the church (Busza et al., 2013; Mackworth-Young et al., 2021), ALHIV avoided intimate relationships (Lawan et al., 2015), delayed their sexual activity (Mattes, 2014) and questioned the possibility for future relationships and marriage (Busza et al., 2013; Gitahi et al., 2020; Kimera et al., 2020b). Those restrictions clearly distinguished their sexual norms from those of their peers (Loos et al., 2013; Mattes, 2014) and made them reluctant to request contraceptive methods (Kaunda-Khangamwa et al., 2020). Due to the fear of infecting others (Busza et al., 2013; Midtbø et al., 2012; Mutumba et al., 2019) and avoiding accusation and stigma, some participants opted to choose an HIV-positive partner (Mattes, 2014; Petersen et al., 2010). In addition, with the longing for independence and “normalcy”, ALHIV struggled with the imposed restrictions on their lived sexuality and disclosure behaviour (Mackworth-Young et al., 2021).

No consequences

Some ALHIV felt no consequences due to their HIV status (Bernays et al., 2015; Maseko & Madiba, 2020). This was evident in their comparison of HIV with other chronic diseases they perceived to be worse than HIV (Chory et al., 2021), but also in an environment, where they received the same treatment as others (Lanyon et al., 2020). The provision of ongoing, appropriate and accurate information regarding HIV made them not only adhere to ART, but also facilitated HIV status acceptance and perceived “normalcy” (Adams & Crowley, 2021; Petersen et al., 2010).

These findings demonstrate that, despite almost four decades with HIV in SSA having passed, stigma and discrimination continue to be a major challenge for ALHIV, impacting their physical and emotional health outcomes. The diversity in ALHIV’s perceived consequences due to HIV seems to result from the interplay between ALHIV’s internalised perceptions, as well as from societies’ perceptions regarding HIV.

2.7.3 HIV management and coping

This main theme included the six subthemes “Perceptions of ART”, “Support structures”, “Stigma”, “Disclosure”, “The power of knowledge” and “Wider determinants of control”.

Perceptions of ART

While ART was perceived as lifesaving and, due to better health, valued as antidote against stigma (Kimera et al., 2020a; Li et al., 2010), simultaneously ALHIV perceived ART as a daily reminder of their HIV status (Madiba & Mokgatle, 2016; Maseko & Madiba, 2020). Strict ART

adherence requirements placed an immense responsibility on ALHIV, being conscious about their dependence and aware that non-adherence is tantamount to a premature death sentence (Gitahi et al., 2020; Mackworth-Young et al., 2017; Pienaar & Visser, 2012). In 23 studies participants believed in ART's effectiveness due to improved health, prolonged life expectancy and because ART prevented physical signs of HIV such as skin rashes, which in turn counteracted the perception of being "different" (Kaunda-Khangamwa et al., 2020; Mutumba et al., 2015). In addition, ALHIV mentioned that ART helps with controlling the virus (Crowley et al., 2019), improved quality of life (Pienaar & Visser, 2012), and increased self-confidence (Loos et al., 2013). Thus, enhanced ART adherence facilitated their ability to cope with the chronic condition (Luseno et al., 2017; Petersen et al., 2010). However, contradicting perceptions regarding ART effectiveness, such as ART being a treatment, not a cure, were described as demotivating and often led to incomplete ART adherence (Dako-Gyeke et al., 2020; Okawa et al., 2017; Yang et al., 2018). Furthermore, ART's integration into their daily routine (Crowley et al., 2019), the fear of being recognised as HIV-positive through ART (Bernays et al., 2015), as well as treatment fatigue (Mutumba et al., 2019) were perceived challenges for ALHIV. Despite ART dependence instigating the perception of being "different" (Kawuma et al., 2014), it also helped destigmatising their condition by making visible signs of HIV invisible (Thupayagale-Tshweneagae, 2010).

Furthermore, ALHIV described discomfort regarding the taste, smell, intake frequency and pill burden of ART (Madiba & Josiah, 2019). While ALHIV perceived the big pill size difficult to swallow (Kunapareddy et al., 2014; Luseno et al., 2017; Madiba & Josiah, 2019), the large pill containers allowed the identification as HIV drug and were therefore considered as risk for stigma (Knizek et al., 2017; Mutumba et al., 2019). Moreover, ALHIV perceived caregivers' ART enforcement, including physical violence and fear-instilling threats for ART non-adherence inappropriate (Bernays et al., 2015; Mackworth-Young et al., 2021). However, in addition to the intimidations from caregivers, the perceived threat by HIV itself, the lack of HIV-related communication and education, as well as feeling "different" contributed to challenges regarding their emotional wellbeing and ability to cope with HIV (Adams & Crowley, 2021).

Support structures

ALHIV perceived support provided by peers and peer support groups, caregivers and healthcare workers as enhancement to control their condition. In particular peer support groups were valued due to the improved knowledge about HIV and the opportunities of openly discussing HIV with peers, experiencing similar challenges and providing a sense of belonging and normalising their condition (Denison et al., 2015; James et al., 2018; Mupambireyi et al., 2014). ALHIV reported improved self-acceptance, enhanced self-management skills and ART

optimism as result of joining a peer support group (Kimera et al., 2020a; Willis et al., 2018). Learning from older ALHIV, who managed their condition positively further furnished them with encouragement (Mackworth-Young et al., 2021; Mupambireyi et al., 2014). However, improved acceptance of their condition was more frequently stated by older, more mature ALHIV (Petersen et al., 2010) indicating that acceptance of HIV occurred as a process over time.

Assistance from caregivers involved practical support by ART reminders, but also emotional support to overcome anxiety, especially during disclosure (Luseno et al., 2017; Okawa et al., 2017). In contrast, lack of caregiver support in form of ART reminders or the absence of supervision at an early age, as well as restrictions by caregivers and stigma in the home environment were perceived as negatively influencing ALHIV's control over their condition (Mackworth-Young et al., 2017; Midtbø et al., 2012).

Healthcare workers were described as a source of support, enabling ALHIV to manage and control their condition through establishing a trustful, confidential and non-judgmental relationship and by the provision of positive counselling messages and information (Hornschuh et al., 2014). Nevertheless, perceptions negatively affecting personal HIV control included poor interactions with healthcare workers, such as inattention to personal concerns and punitive ART adherence counselling (Woollett et al., 2017). Furthermore, the transition from paediatric to adult HIV care increased ALHIV's perception of being in control of their own health. This responsibility often increased with age and, especially older ALHIV, aged 16-19 years, were found more resilient in their self-management (Loos et al., 2013), thus, adequate information and a progressing approach, accompanying ALHIV to active commitment in self-management has been perceived as effective (Doat et al., 2021).

Stigma

HIV-related stigma and discrimination, as previously discussed, caused emotional distress and has been considered as negatively impacting the perceived control of HIV through ART adherence and retention in care (McHenry et al., 2017). However, silence and secrecy were perceived as a control strategy against HIV-related stigma (Appiah et al., 2019; Mutumba et al., 2015).

Disclosure

ALHIV perceived a better control over HIV after being disclosed, as this helped them understanding and take responsibility for their life situation. It improved their self-care, quality of life (Mutumba et al., 2019) and ART adherence, which, furthermore was perceived crucial for preventing HIV onward transmission (Okawa et al., 2017). Disclosing their HIV status to

others was necessary for requesting and receiving support, however, this stood in sharp contrast to the fear of discrimination following disclosure (Enimil et al., 2016), influencing their identity and emotional illness perceptions. Additionally, ALHIV perceived delayed disclosure, after the recommended age of 12 years, and silence around the mode of HIV acquisition as negatively affecting their self-acceptance (Gitahi et al., 2020; Maseko & Madiba, 2020; Woollett et al., 2017). Moreover, ALHIV who were not aware of the reason for taking daily ART, perceived these drugs as gratuitous since they were not feeling sick (Kunapareddy et al., 2014). Therefore, ALHIV preferred disclosure at an appropriate age, using a gradual, continuous approach, preparing them for the day of full disclosure (Maseko & Madiba, 2020).

However, to avoid HIV-related discrimination, ALHIV perceived the need for secrecy surrounding their condition, including hiding their ART and HIV status concealment, which complicated ART adherence (Kawuma et al., 2014; Kunapareddy et al., 2014). Thus, attempts to control circumstances around the involuntary HIV status disclosure compromised ART adherence, which in turn compromised control of their viral load. The tremendous fear of involuntary HIV status disclosure made ALHIV perceive ART as a social risk and themselves as “different” to their peers (Bernays et al., 2015; Crowley et al., 2019). Recurrently instructed by their caregivers, ALHIV minimised the number of people they revealed their HIV status to, including people at school, the workplace, the neighbourhood and even within their homes (Midtbø et al., 2012; Mutumba et al., 2015).

The school as an important environment for social interactions aroused challenges regarding ART adherence due to the fear of being recognised as HIV-positive and struggling with subsequent stigma. This was specifically true for ALHIV learning at boarding schools, providing only limited privacy for medication intake (Madiba & Josiah, 2019). For maintaining their secret, ALHIV often felt in need of lying about their condition (Mutumba et al., 2015) or refraining from school trips (Kunapareddy et al., 2014). There is a clear link between late disclosure, the lack of HIV-related communication and the subsequent inability to disclose their HIV status to others (Zanoni et al., 2020). Furthermore, ALHIV stood between the conflicting advice given by caregivers not disclosing their HIV status to protect themselves and the family from discriminatory experiences, and the healthcare workers’ instruction to disclose their HIV status for facilitating support from the wider social environment and to intimate partners for the prevention of HIV onward transmission (Okawa et al., 2017).

The power of knowledge

In order for ALHIV to control and accept their condition, education on HIV was mentioned as beneficial to understand the importance of ART, consequences for not adhering to ART and

ways of living positively with the virus (Appiah et al., 2019; Petersen et al., 2010). Opposing the interpretation of HIV as a manageable condition meant the view of HIV as a frightening infection, highlighting the need for knowledge through the provision of accurate information (Mupambireyi et al., 2014). Nevertheless, ALHIV registered deficient communication about HIV in general (Enimil et al., 2016; Mupambireyi et al., 2014; Mutumba et al., 2019), discomfort talking about their condition (Crowley et al., 2019) and lack of trust or empowerment to communicate HIV-related topics (Adams & Crowley, 2021; Mutumba et al., 2019). This reticence compromised their information-seeking and knowledge about HIV, resulting in ALHIV's perceived limited control of their condition. Moreover, ALHIV's hesitancy was reflected in communication with caregivers and healthcare workers concerning ART non-adherence due to ALHIV's trepidation of negative consequences, often causing feelings of guilt and perceived lack of control among ALHIV (Bernays et al., 2015; Hornschuh et al., 2014; Mackworth-Young et al., 2017).

Wider determinants of control

Religious or spiritual activity was perceived as a positive and negative HIV control factor. It aided in positively controlling HIV-related distress through enhancing hope and acceptance (Abubakar et al., 2016; Chory et al., 2021; Kimera et al., 2020a), while conversely, ALHIV felt punished by God for their condition (Denison et al., 2015; McHenry et al., 2017). Furthermore, religious healing practices often led to poor ART adherence, and thus, education is vital to highlight the importance of continued ART alongside religious practices (Mutumba et al., 2015). In addition, poverty was reported both as a consequence of HIV and as a factor negatively influencing the personal control required for effectively managing the condition. ALHIV stated that insufficient funds to afford the transportation fare to hospital, inability to pay for drugs treating ART side effects and lack of nutrition, resulted in ART adherence challenges and thus, limited their control of their condition (Knizek et al., 2017; Luseno et al., 2017).

In conclusion, while ALHIV perceived controllability over HIV through trusting in ART, stable support structures, knowledge and acceptance of their HIV status, they felt unable to change the negatively influencing stigmatising attitudes of the wider society. Secrecy has been perceived as a protective strategy for coping with HIV, however this can have detrimental implications through compromising ART adherence, and thus control of viral load.

2.7.4 Emotional HIV illness perceptions

This main theme was divided into negative and positive emotional illness perceptions; however, the themes disclosure and ART were both perceived as positive and negative by ALHIV.

Negative emotional illness perceptions

The most frequently mentioned negative emotional illness perceptions were due to HIV-related stigma. Fear of stigma and the resulting need for secrecy were mentioned in 26 studies. Anxiety of rejection and abuse by family and friends, as well as experienced discrimination led to feelings of shame, sadness, loneliness and depression, and in some cases extending to self-rejection and suicidal tendencies (Kimera et al., 2020a; Knizek et al., 2017; McHenry et al., 2017). While stigma in the home environment led to internalised stigma, frustration and anger (Dako-Gyeke et al., 2020), at school, experienced discrimination made ALHIV feel “different” from their peers, increased their anxiety and often led to lack of concentration (Appiah et al., 2019; Callen et al., 2022; Lanyon et al., 2020). Furthermore, the fear of discrimination was identified as a barrier to disclosing their HIV status to friends and intimate partners (Adams & Crowley, 2021; Enimil et al., 2016). HIV-related stigma has already been discussed under the themes HIV identity, consequences of living with HIV and HIV management and coping, thus underlining the theme’s significance.

Emotions after disclosure

ALHIV responded to being made aware of their HIV diagnosis mostly with negative emotions. Feelings of shock due to being unexpectedly told that they have this “dangerous condition” has been reported regardless of ALHIV’s age (Kunapareddy et al., 2014; Luseno et al., 2017; Mackworth-Young et al., 2021), followed by anger, blaming the parents for the condition and for not disclosing earlier, as well as for concealing the truth for a long time (Mattes, 2014; Otieno & Obuya, 2019). Moreover, sadness, hopelessness, confusion, fear of imminent death, worry, depression, suicidal tendencies, disbelief and disappointment have been identified as emotions after being made aware of their HIV diagnosis (Katirayi et al., 2021; Luseno et al., 2017; Midtbø et al., 2012). A gradual acceptance of their HIV status, as described under the theme HIV management and coping, took often more than one year (Gitahi et al., 2020). However, ALHIV also mentioned feelings of relief following disclosure, especially when provided with appropriate information prior to disclosure and when the disclosure process followed a stepwise approach (Madiba & Mokgatle, 2016; Mburu et al., 2014a).

Negative emotions regarding HIV in general

Negative emotions regarding HIV in general included negative self-perceptions as a consequence of internalised stigma, feelings of shame and low self-worth, depression and anxiety regarding the virus and the nature of HIV (McHenry et al., 2017; Phuma-Ngaiyaye & Dartey, 2015; Yang et al., 2018). Additionally, ALHIV revealed frustration due to opportunistic infections causing poor performance in school, anger towards the virus, as well as inability to accept their HIV status, impeding the recognition of HIV as part of ALHIV's identity (Kaunda-Khangamwa et al., 2020; Woollett et al., 2017), thus negatively impacting disease control.

Negative emotions regarding ART and HIV care

Linked to the theme HIV management and coping, anxiety and annoyance were stated by ALHIV regarding ART as required lifelong treatment, their ART dependence, their pre-disclosure unawareness for ART intake, but also the lack of empathy from adults for ALHIV's reasons for ART non-adherence (Chory et al., 2021; Kimera et al., 2020b; Li et al., 2010). However, despite ALHIV's desire to be "normal", they perceived themselves as "different", which was mainly due to ART and HIV-related stigma, instigating feelings of sadness, hopelessness and distress (Callen et al., 2022; Crowley et al., 2019; Mutumba et al., 2019). Negative emotional perceptions concerning the hospital derived from feelings of being judged and not treated confidentially by healthcare workers (Mutumba et al., 2015; Van der Merwe & van der Merwe, 2020), but also from fear of consequences for ART non-adherence (Mutumba et al., 2015; Woollett et al., 2017), leading to self-blame and concealing ART non-adherence (Kawuma et al., 2014; Mackworth-Young et al., 2017). Consequently, ALHIV miss out on opportunities of open discussions regarding ART adherence challenges and eliciting possible solutions for improved adherence.

Worries about the future

Worries about their future were expressed, especially regarding intimate relationships and marriage, giving birth to an HIV-negative child and the impact of HIV on their education and employment (Busza et al., 2013; Mutumba et al., 2019; Otieno & Obuya, 2019). Furthermore, as described under the subtheme HIV duration, the fear of premature death, accentuated by the experience of losing a parent due to HIV, silence regarding death, particularly HIV-related death and the awareness of the absence of a cure for HIV has been pointed out (Kimera et al., 2020a; Lawan et al., 2015; Loos et al., 2013).

Lack of information

Insufficient information concerning the mode of HIV acquisition were perceived as emotionally depressing and often led to self-blame (Appiah et al., 2019; Dako-Gyeke et al., 2020; Maseko

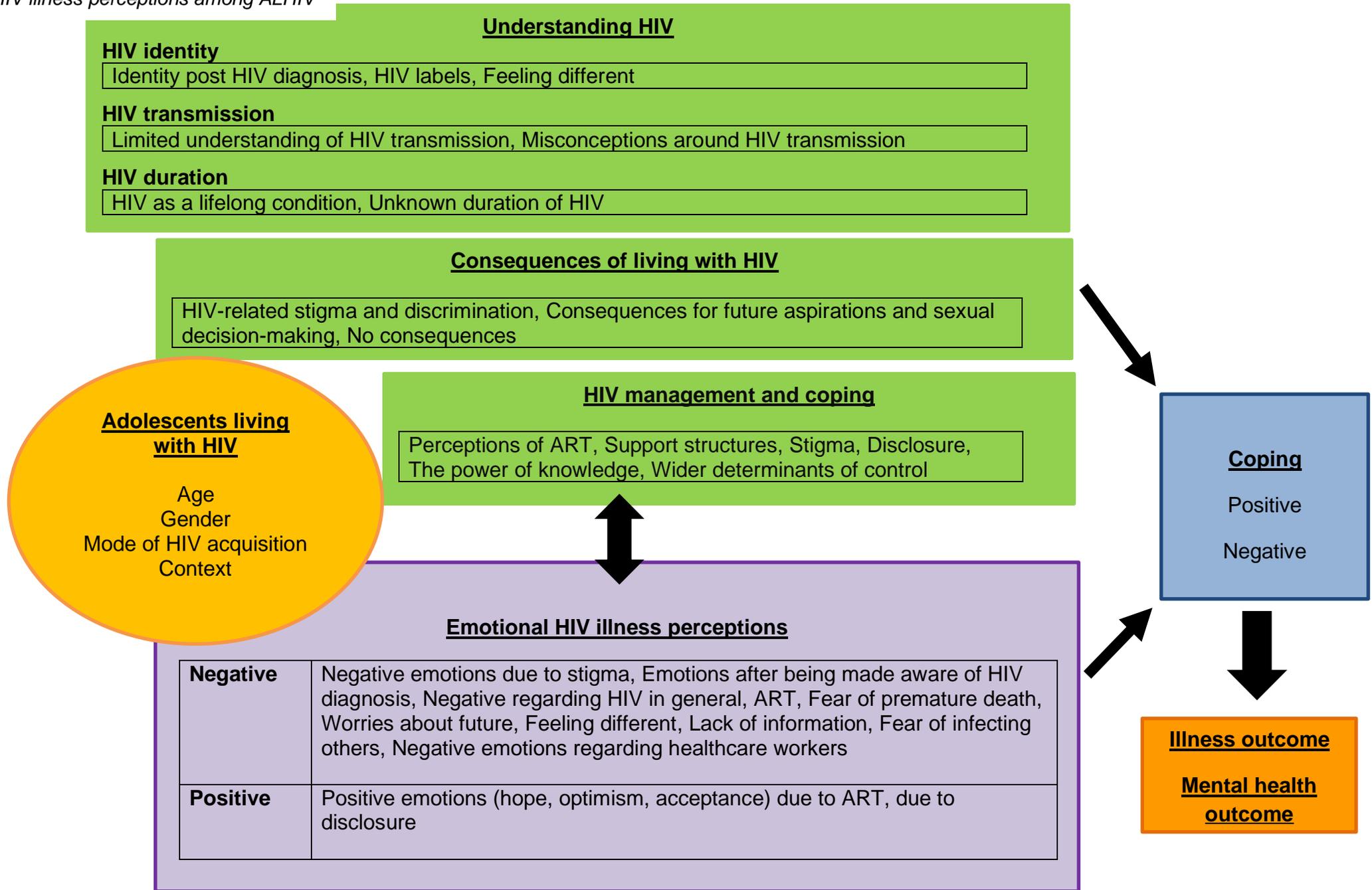
& Madiba, 2020). Inadequate knowledge on the duration of their condition and treatment, as well as on measures to prevent HIV mother-to-child transmission caused worry, since they felt uncomfortable enquiring about these issues (Gitahi et al., 2020; Madiba & Mokgatle, 2016). Furthermore, ALHIV felt incompetently informed prior and during disclosure, particularly regarding the purpose for taking daily drugs, instigating worries and anger (Mutumba et al., 2019; Woollett et al., 2017). The absence of open discussions regarding HIV made ALHIV feel “trapped in a world of lies” (Pienaar & Visser, 2012). Likewise, the fear of infecting others through sexual contact, but also through usual interactions, such as playing, dismantled their self-image and made ALHIV feel like they were a threat to others (Kimera et al., 2020b; Mattes, 2014), corresponding with the frequent discriminatory experiences they encounter. Also here, the absence of correct information and support places ALHIV in a dilemma deciding between disclosing their HIV status and risking rejection or hiding their HIV status and their ARTs, which may increase the likelihood of HIV onward transmission. The impact of insufficient and inaccurate information has been previously discussed under several themes, evidencing a fundamental need to take those findings into account during the planning of interventions for this population.

Positive emotional illness perceptions

ALHIV also expressed positive emotional illness perceptions, such as optimism regarding their future, which was linked to their faith, hope for a cure, and acquiring knowledge about prevention of HIV mother-to-child-transmission (Woollett et al., 2017). Furthermore, sometime after disclosure and with the provision of adequate knowledge on HIV, ALHIV felt able to accept their HIV status as part of their identity (Gitahi et al., 2020). Through attending peer support groups, ALHIV learnt to feel “normal” and expressed happiness knowing they were not the only ALHIV (James et al., 2018; Mupambireyi et al., 2014). Moreover, with the confidence in ART, ALHIV even felt healthy or “normal” and therefore, the availability of ART made them feel safe (Adams & Crowley, 2021; Midtbø et al., 2012).

In summary, emotional illness perceptions among ALHIV were mainly negative due to HIV-related stigma and inadequate information regarding HIV. The value of peer support was recognised in helping ALHIV to manage their condition successfully, and to counteract negative emotional responses. Figure 2.2. visualises the main themes and subthemes with their relationships.

Figure 2.2.
HIV illness perceptions among ALHIV



2.8 Discussion

This literature review on HIV illness perceptions among ALHIV in SSA included 54 studies that were conducted in ten SSA countries and published in English between 2010 and 2022. The findings portray a comprehensive picture of how ALHIV perceive their condition concerning the nature, cause and duration of HIV, the consequences they experience due to living with HIV, and their management, coping mechanisms and emotional responses to HIV. Those themes appeared to be interrelated and impacted upon each other. Despite the availability of ART and scientific consensus on its benefits for reduced morbidity and mortality, as well as for preventing HIV onward transmission, perceptions of HIV among many ALHIV were negative. HIV-related stigma and discrimination, in addition to a crucial lack of information, emerged as major influences on ALHIV's illness perceptions.

HIV-related stigma and discrimination made ALHIV feel different from others, enhanced their mistrust and clearly impacted negatively on their perceived control of HIV, but also on their mental health, including feelings of devaluation and shame. Furthermore, HIV-related stigma often diminished ALHIV's educational and life choices, leading them into a double life, in which they purposefully used secrecy as strategy for protection and coping with HIV. However, this approach frequently compromised their ability to realise the benefits of ART and this consequently affected their adherence, jeopardising not only their own health, but also those of their intimate partners.

Moreover, ALHIV experiencing disclosure at an older age, having been subjected to HIV-related secrecy and lies concerning their condition over a period of time, displayed more challenges adhering to ART and were only able to accept the condition as part of their identity at a later stage in life. Therefore, accurate, age-appropriate and ongoing information and discussions regarding HIV are essential for ALHIV's emotional wellbeing and the facilitation of self-management skills, specifically ART adherence behaviour. This can be achieved through open communication with caregivers and provision of support to facilitate disclosure appropriately, but also during clinic appointments or peer support group meetings. While caregivers often inhibited disclosure to others, healthcare workers encouraged ALHIV to disclose their HIV status to enable access to support, but also to reduce the risk for HIV onward transmission, which should be prioritised, considering that ALHIV may have their first sexual experiences during adolescence. Therefore, the collaboration with caregivers may further assist in coherent advice conveyed at home and in the clinic, specifically regarding HIV status disclosure.

Research has demonstrated the supportive effect of appropriate health education on the development of positive illness perceptions (Fortenberry et al., 2014; Iskandarsyah et al., 2013). Nevertheless, in this context, it is important to timely place emphasis on the needs of ALHIV in order to modify illness perceptions and thus, enhance coping strategies and achieve adequate illness and mental health outcomes (Petrie et al., 2007). Despite ALHIV's perceptions of HIV having an impact on how they see themselves and live their lives, these perceptions can be influenced by others, both positively and negatively. Consequently, peer support groups have been mentioned repeatedly as constructively impacting the perceptions of HIV since they provided a safe environment for discussing HIV-related topics, improving peoples' knowledge on HIV, which impart a sense of belonging and "normalcy" and thus, enhance ALHIV's acceptance of their HIV status and coping. Nevertheless, critical efforts to modify ALHIV's negative illness perceptions through the development of culturally appropriate, youth-centered HIV education for ALHIV are deemed necessary, also including those ALHIV not accessing peer support groups. Furthermore, educational strategies on national levels, addressing HIV-related knowledge gaps among communities, specifically focusing on modes of HIV acquisition - including the messages concerning "ART as prevention" and "Undetectable=Untransmittable" ("U=U") - may aid in the elimination of pervasive stigma and serve not only PLHIV, but also those at risk of HIV acquisition.

Strengths and limitations

A strength of this review includes the extensive search strategy. However, placing language restrictions in the search strategy, limiting the findings to English and German, may have introduced language bias. Furthermore, given the focus on ALHIV in the SSA context, the findings may not be generalisable to other populations. Additionally, as the studies predominantly included ALHIV who acquired HIV perinatally, results cannot be extrapolated to adolescents who acquired HIV through other routes, and thus, research including this population group is recommended. While the methodologies in the studies included relied prominently on IDIs and FGDs, the use of arts-based research methods - due to their non-verbal approach - may further enhance the understanding of adolescents' illness perceptions.

Implications for research and practice

This systematic review identified a number of key knowledge gaps. While most studies examined illness perceptions around the lived experiences among ALHIV from an external point of view, an internal perspective regarding ALHIV's perception of the HIV-virus itself may enhance our understanding regarding the relationships they have with the virus, the perceived threat from the virus in their bodies and the sources influencing their imagination or visualisation of the virus. Perceptions among ALHIV regarding the visual imagination of the

HIV-virus and their translation into coping strategies and emotional wellbeing were not identified. In addition, literature on the terms used for HIV in local SSA languages and their impact on HIV illness perceptions were scarce. Further research in this field should incorporate HIV illness perceptions in view of visual aids used in health education, the impact of terms applied to HIV and the imagination of the HIV-virus among ALHIV in order to modify their negative illness perceptions and thus, achieve improved mental health and illness outcomes.

2.9 Conclusion

This literature review identified 54 studies that revealed multiple HIV illness perceptions among ALHIV in SSA. The main factors negatively influencing ALHIV's illness perceptions include HIV-related stigma and a crucial lack of information on HIV. Perceptions regarding visual aids used in health education and the visual imagery of the HIV-virus were not identified, whereas perceptions on local terms used for HIV in this context were rare. Research, preferably using arts-based methods in these areas, may enhance the comprehension of ALHIV's illness perceptions and their needs. Thus, they may guide the development of culturally and age-appropriate educational material, which may improve peoples' understanding of the condition and its requisite strategies.

CHAPTER 3: METHODOLOGY

3.1 Introduction

This chapter explains the methodology and methods used for this research in order to fill the identified gap in the literature review by seeking to answer the following research question “In what ways do adolescents living with HIV in Malawi imagine the HIV-virus and how do these images and the language used for HIV impact on their emotional wellbeing, perceptions and lived experiences?”. The ensuing sections present the research philosophy, the theoretical framework and the justification for a qualitative phenomenological research design, employing ALHIV in Malawi. In addition, the methods, including the research setting, population, recruitment, data collection, as well as data management and analysis are outlined. Lastly, the ethical considerations and the trustworthiness and rigour of the research will be discussed.

3.2 Research philosophy and positionality

Research philosophy

In consideration of the study's focus on the subjective experience, an inductive, qualitative phenomenological methodology was used to explore ALHIV's individual lived experiences and perceptions, and the interplays with their emotional wellbeing. Therefore, this study was positioned within a constructivist paradigm to appreciate the value-laden, pluralistic realities of the participants. This allowed the study to capture and integrate the complexity of themes evolved from the data and their shared meanings (Ormston et al., 2014). In line with the constructivist worldview, a relativist ontology (nature of reality or existence) and subjectivist epistemology (nature or study of knowledge) guided the methodology and methods, as ALHIV's multiple realities depend on their context and are constructed and expressed through social exchanges, as well as through the use of language (Frowe, 2001; Lincoln et al., 2011). However, the researcher's sympathetic and close contact and interaction with the research participants during the data collection process influenced their realities throughout the research, and thus, the researcher's reflexivity regarding the own contributions to the findings was vital (Guest et al., 2012).

Positionality

Recognising one's own positionality as a researcher is essential since diverse personalities may impact on a study's process, findings and conclusions (Vanderbeck, 2005). As a female, middle aged nurse from Germany, working for over 10 years in Malawi, the researcher was aware of the imbalanced relation to the study participants due to their different cultural

backgrounds, as well as differences in age, gender, education and economic status. Furthermore, being influenced by the professional background in nursing, the researcher needed to distance herself from purely biomedical explanations regarding HIV to facilitate a more holistic understanding and interpretation of ALHIV's accounts. However, with the previous experiences of working with ALHIV, the researcher was able to use her familiarity with the subject area when conducting the study. In recognition of her own position, the researcher mitigated power relations through reflexivity, the creation of a non-threatening environment for data collection and the inclusion of accessible, youth-friendly language during conversations (Horstman & Bradding, 2002; Randall et al., 2013). Additionally, continuous reflexivity allowed the researcher to approach own biases, which may have impacted upon the research throughout the research process (Macbeth, 2001).

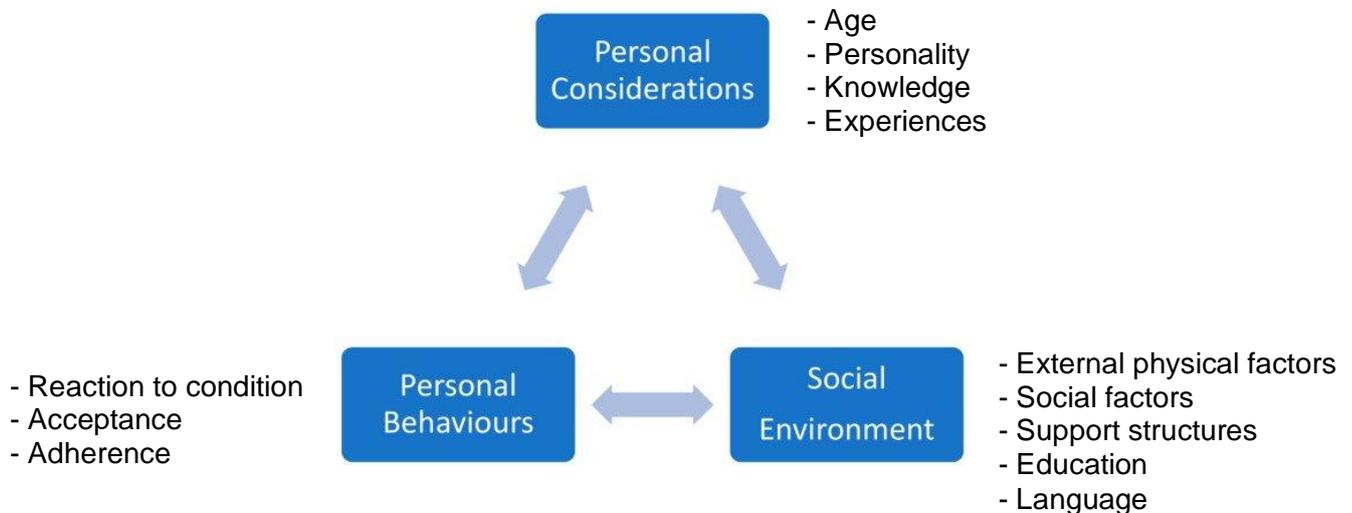
3.3 Theoretical framework

To understand the ways ALHIV imagine the HIV-virus and how these images and the language used for HIV impact on their emotional wellbeing, perceptions and lived experiences, Bandura's social cognitive theory (SCT) was employed (Bandura, 1991). Introduced in the 1960s, social learning theory places its focus on behaviour change through internal or external reinforcement, for instance using a rewarding system, that can positively or negatively influence behaviour. Bandura then expanded and developed these ideas to introduce SCT in 1986 due to the central recognition of the cognitive functions that impact on human learning and behaviour (Bandura, 1986). SCT implies that individuals' learning takes place in social contexts through cognitive processes and the interactions of the three domains, namely the personal, environmental and behavioural components, that modify behaviours, which in turn reflect their values (Bandura, 1986). This three-directional system functions reciprocally as outlined in Figure 3.1.

The SCT pays attention to individuals' previous experiences in regard to the motivations, emotions and reasons for acquiring specific behaviours and attitudes within their social contexts. However, SCT regards knowledge not as passively accepted through solely environmental sources, but rather as a product entailing individuals' agency and active control over their learning by reflecting on possible outcomes of their behaviour, which impacts on their personal and environmental factors and thus, modifies behaviour (Schunk & Usher, 2012). Nevertheless, the personal agency depends on several aspects, including individuals' aims, self efficacy and ability to reflect on and evaluate their experiences and behaviour (Locke, 1997).

Figure 3.1.

Bandura's Model of triadic reciprocal causation (Bandura, 2001)



Bandura's SCT provides a valuable structure for apprehending individuals' learning, understanding and behaviour in different populations, age groups and various subject areas, such as in psychology, as well as in educational, social and health sciences. Regarding the application of the SCT in HIV prevention research, Bandura (1994) himself employed the SCT for explaining the influences of personal, environmental and behavioural factors on individuals' decisions concerning HIV testing and risk behaviours. He suggested that, because knowledge alone may not impact on behaviour change, the consideration of his triadic model in interventions to be more effective. A systematic review exploring the effectiveness of behaviour change interventions for HIV prevention for 12-24 year old participants in SSA, included 17 articles - of which most used the SCT as a framework for the development or the evaluation of an intervention (Mwale & Muula, 2017). Moreover, several studies in HIV and sexual health promotion employed the SCT to align their results to the SCT domains (Dos Santos, 2020; Merlin et al., 2018; Muessig et al., 2018; Nall et al., 2019; Winskell et al., 2018).

Other theoretical models, widely used in HIV research, were considered for this study, such as Rosenstock's (1974) Health Belief Model, which focuses on health behaviour prediction in view of perceptions concerning illness susceptibility, illness severity, benefits of behaviour and barriers to behaviour change - but due to its inattention to individuals' identity and emotions it was considered not to be suitable for this study. Also, the Common-Sense Model (Leventhal et al., 1992), emphasising cognitive and emotional illness perceptions was deemed inappropriate since the model excludes the environmental domain (Broadbent et al., 2019), a

crucial element in this study since health behaviour depends on the dynamic interrelation between the individual and their social environment (Bronfenbrenner, 1979).

Since the SCT allows the accommodation of synergies between cognitive, behavioural and emotive measures, including socio-cultural contexts, it was considered the most appropriate theoretical lens for this study (D'Cruz, 2003). It is applicable to gain an understanding of ALHIV's experiences and perceptions concerning HIV, and is therefore relevant to HIV communication and education strategies. Also, the SCT's assumptions that individual's functioning and wellbeing rely on the identification of the facilitators and barriers within the three interrelated domains (Bandura, 1986) was deemed relevant for this study in order to understand the factors impacting on ALHIV's emotional wellbeing.

3.4 Qualitative research design

In contrast to quantitative research that aims to establish evidence objectively, for this study a qualitative research design was employed for exploring the personal meanings embedded within the multiple subjective realities (Creswell & Poth, 2016; Crotty, 1998). Quantitative approaches are applicable for various quantifiable research purposes, but would have impeded the attainment of an in-depth understanding of the complex, contextualised phenomena in this research project (Silverman, 2017). In accordance with the study aim, to explore descriptions, perceptions and representations of the HIV-virus among ALHIV, and to examine the impact of these interpretations on their emotional wellbeing, a qualitative and inductive methodology was utilised. This enabled the researcher to actively interact with the participants to gain a mutual and comprehensive insight into their perceptions (Denzin & Lincoln, 2008), which was important in view of the sensitive research topic. The methods used in qualitative research include ethnography that pays attention to diverse cultures, narratives use stories to gain access to personal experiences, case studies intensively concentrate on individuals or groups, grounded theory intends to generate theories by exploring social practices, and phenomenology is frequently employed when aiming to uncover experiences or certain phenomena, which this study hoped to achieve (Denzin & Lincoln, 2008; De Vos & Fouche, 1998).

3.4.1 Hermeneutic phenomenology

Rooted in philosophy, phenomenology is a qualitative method of inquiry, employed to access a comprehensive, in-depth understanding of the meaning of personal perceptions and lived experiences (Bryman, 2016). To comprehend the emotional states towards and relevance of phenomena, the individuals' context plays a major role since experiences are generated within diverse social contexts (Neubauer et al., 2019). The two distinct orientations within

phenomenology include descriptive and interpretive approaches (Creswell & Poth, 2016). Husserl, the founder of phenomenology, developed descriptive transcendental phenomenology to examine individuals' lived experiences to describe the essence of specific phenomena devoid of any kind of interpretation (Husserl, 1931; Moustakas, 1994). To avoid assumptions, judgement and biased findings, the researcher requires to be detached from own experiences, called epoché or bracketing, so that objectivity can be achieved (Moustakas, 1994). In contrast, the interpretive, hermeneutic phenomenology, as proposed by Heidegger (1962), aims to interpret and understand complex phenomena in depth within the context they are occurring (Creswell & Poth, 2016; Vandermause & Fleming, 2011). Since individuals cannot be separated from the world they are living in and the language used in this context, both need to be considered when interpreting the phenomena under investigation (Braun & Clarke, 2013). According to Heidegger (1962) experience is a process, which is shaped through individuals' interpretation of the experienced within the social context and is expressed through language. The interpretative nature of hermeneutics obliges the researcher to exert self reflection since these reflective accounts require an entrenchment within the process of interpretation, with the findings not disengageable from the interpreter's own perceptions and experiences (Laverty, 2003).

As this research not only sought to present a description of ALHIV's lived experiences and perceptions, but to explore and interpret these experiences from the viewpoint of ALHIV with their reflections on these experiences in consideration of the underlying meaning, this approach was found to be suitable (Friesen, 2012; Van Manen, 2016). Since ALHIV's perceptions and lived experiences of HIV are shaped by their social context, hermeneutic phenomenology's focus on the context and language further contributed to a holistic understanding of the researched topic (Van Manen, 2016). Moreover, hermeneutic phenomenology is consistent with the philosophical stance of this research, considering the ontological question "What does it mean to live with HIV?" being central for this study's enquiry. Additionally, due to the sensitive research topic and the inclusion of a vulnerable population, the need for an empathetic, but reflective engagement of the researcher as part of the research was deemed crucial, hence, a hermeneutic phenomenological approach was found most appropriate for this study.

The hermeneutic phenomenological approach has been effectively employed in HIV-related research worldwide including different populations, contexts and age groups (Crowley et al., 2019; Doat et al., 2021; Mohammadpour et al., 2009; Rose et al., 1998; Ross et al., 2007; Stroumpouki et al., 2020) and was found beneficial for foregrounding adolescents' experiences and perceptions since their voices are often ignored (Pincock & Jones, 2020). Despite the

strengths of hermeneutic phenomenology, criticisms regarding its subjectivity, small sample sizes and biased interpretation of the findings were recognised (Stephenson et al., 2018). However, the strengths of this methodology outweighed the limitations and by the researcher's awareness of their own predispositions potentially affecting the data collection, continuous reflection aided in minimising interpretation bias (Whitehead, 2004).

3.5 Methods

This section presents the research setting, the research population including the eligibility criteria, the sample size, recruitment and sampling methods. Furthermore, the four phases of data collection are discussed, followed by the justification for the choice of drawing as an arts-based research method to explore ALHIV's imaginations of HIV. Finally, the data management and analysis are presented.

3.5.1 Research setting

With a population of about one million people, Lilongwe city (Figure 3.2.) is situated in the central region of Malawi (NSO, 2019), which, according to International Center for AIDS Care and Treatment Programs (2022), has a higher HIV prevalence of 10.6% compared to the country's average prevalence of 8.9%. The study was conducted in Lilongwe, the capital city of Malawi, in one of the main urban, long established HIV clinics in the country, which has extensive experience in caring for children and ALHIV. The availability of a peer support group for ALHIV made this setting convenient for the recruitment of participants and for conducting the IDIs and FGDs, since this location is a well-known environment for the study's participants.

Figure 3.2.

Map of Malawi with Lilongwe as research site (Economist Intelligence, 2022)



3.5.2 Research population, eligibility criteria and sample size

Research participants consisted of ALHIV, who attended a peer support group at an HIV clinic in Lilongwe and service providers working at this clinic, such as clinical staff involved in the care for ALHIV, HIV peer support group coordinators and HIV counsellors. The eligibility criteria for the study enrolment are outlined in Table 3.1. Given the vulnerability of the adolescent research participants, the capacity to give consent was an important inclusion criteria (Biros, 2018). The inclusion of only ALHIV, who were aware of their HIV status prior to their recruitment, was based on the endeavour to avert potential distress during data collection as HIV is a sensitive topic for discussion. Including service providers participating in this research was perceived as an advantage for gaining perspectives and interpretations of the findings from experts in that field, who may usually interact with the ALHIV on a more personal level.

Table 3.1.

Eligibility criteria for research participants

Research participants	Inclusion criteria	Exclusion criteria
Adolescents living with HIV	(a) Aged 10 to 19 years (b) Living with HIV (c) Knowledge of their HIV status (d) Capacity to give consent (e) Consent by caregivers for participants, who are under 18 years old	(a) Unaware of HIV status (b) No consent by caregivers for participants, who are under 18 years old
Service providers	(a) Employed at the HIV clinic as clinical staff, HIV peer support group coordinators or counsellors for ALHIV (b) Experience of at least 1 year working with ALHIV to ensure they have sufficient competence in this topic area (c) Consent to participate in the study	(a) Students on clinical placement in the HIV clinic (b) Experience of less than 1 year working with ALHIV

The recommended sample size for phenomenological studies varies from 1-12 participants (McIntosh-Scott et al., 2013) to 5-25 participants (Creswell & Poth, 2016). However, Braun and Clarke (2021) question the usefulness of predefined sample sizes since data saturation in reflexive TA is a subjective conception. In order to collect sufficient data for answering the research question, this study recruited 16 ALHIV and five service providers, which allowed

different layers of interpretation of the drawings, including the viewpoint of the individual ALHIV, ALHIV in a group and service providers as experts working with this population. In order to collect sufficient data, this study recruited 16 ALHIV and five service providers. Demographic information of the participants is outlined in Table 3.2 and 3.3.

Table 3.2.

Demographic information of adolescent participants

Name*	Gender	Age**	Age** at disclosure	Disclosed by	Orphan status	School grade
Lydia	Female	13	12	Counsellor	Paternal	Standard 8
Thalandira	Female	13	11	Mother	Non-orphan	Standard 7
Shanita	Female	14	10	Mother	Paternal	Standard 6
Patuma	Female	14	12	Counsellor	Paternal	Standard 5
Chisomo	Female	15	14	Doctor	Non-orphan	Standard 5
Amina	Female	16	11	Doctor	Maternal	Standard 8
Ndazona	Female	17	15	Mother with doctor	Paternal	Form 3
Anne	Female	18	13	Mother	Paternal	Form 2
Mishello	Male	10	8	Mother	Non-orphan	Standard 4
Mkango	Male	12	8	Mother	Paternal	Standard 6
Woimba	Male	12	10	Doctor	Non-orphan	Standard 5
Lion	Male	13	11	Doctor	Non-orphan	Standard 4
Elmore	Male	15	12	Counsellor	Paternal	Form 1
Jonathan	Male	15	12	Hospital staff	Non-orphan	Standard 6
Lovemore	Male	16	15	Doctor	Non-orphan	Form 1
Daligo	Male	18	12	Mother	Non-orphan	Dropped out at Form 1

*All names are pseudonyms chosen by the participants **Age in years

Table 3.3.

Demographic information of service providers

Name*	Gender	Age**	Function at hospital	Years of experience working with ALHIV
Eveless	Female	32	Community health worker and counsellor	7
Martha	Female	60	Nurse	5
Daniel	Male	26	Nurse and mentor	8
John	Male	31	Mentor	9
Steve	Male	41	Clinical officer	10

*All names are pseudonyms **Age in years

All ALHIV were aware of their HIV status and while most participants reported having acquired HIV through mother-to-child transmission, some were unsure of how they obtained HIV. All, except two participants, lived with their biological parent/s; seven were paternal orphans and one was a maternal orphan; all were on ART and attended an HIV peer support group for adolescents. The service providers had between 5-10 years experience working with ALHIV; indeed two lived with HIV themselves. In total 32 IDIs and five FGDs were conducted with a duration of 50 to 165 minutes, giving 51.7 hours of audio recorded data and 25 drawings.

3.5.3 Recruitment and sampling

After obtaining ethical approval (Appendices 6-8), the researcher introduced herself to the staff involved in the care for ALHIV to build rapport. Peer support group coordinators for ALHIV served as gatekeepers to facilitate the recruitment process and to announce the study in accessible language during peer support group meetings with the purpose of identifying suitable participants. Interested ALHIV, who were under 18 years old, received the participant information sheet (PIS) for themselves (Appendices 11-14) and their caregivers (Appendices 15, 16) in Chichewa, which described the study's aim and activities. A meeting with both, the ALHIV and their caregivers, was requested for allowing them sufficient time to make an informed decision.

The recruitment took place from July to December 2021. However, since the recruitment process was slow, support group coordinators telephoned known ALHIV and their caregivers to notify them about the research. For this amendment, ethical approval was obtained (Appendices 9, 10). Those interested in participating contacted the principal investigator and subsequently, a personal meeting was organised to provide further information on the study, to answer questions and for both, the ALHIV and the caregiver to sign the assent/consent form (Appendices 18, 19, 22, 23). ALHIV aged 18 and above received the required information about the study and the PIS individually and were able to consent for participation on their own (Appendices 20, 21). The same applied for the service providers involved in the study (Appendices 17, 24).

Purposive sampling, as commonly used in phenomenological studies, was used to select participants based on the researcher's subjective judgement for being able to collect data from participants, who gained lived experiences on the same phenomenon (Creswell & Poth, 2016; Denzin & Lincoln, 2011; Reid et al., 2005). For being able to answer the research question, the participants were grouped according to age and gender and they were selected in consideration of predefined eligibility criteria. The sample was drawn from ALHIV attending

an HIV peer support group and some ALHIV were contacted directly by the research assistants. The service providers were approached by the researcher personally to identify suitable and interested participants for the FGD.

As ALHIV have distinct characteristics that may impact their participation, they were categorised into four homogeneous groups for the FGDs (Table 3.4.) to reduce power imbalances and to increase participant comfort and candour (Barbour, 2014). Including four participants in each of the FGDs permitted the participants to feel more comfortable discussing sensitive topics and allowed the provision of a sufficient variety of participants’ lived experiences and perceptions (Irwin & Johnson, 2005).

Table 3.4.
Composition of the focus groups

Group	Composition	Number of participants
1	Female ALHIV aged 10-14 years	4
2	Female ALHIV aged 15-19 years	4
3	Male ALHIV aged 10-14 years	4
4	Male ALHIV aged 15-19 years	4
ALHIV total		16
5	Clinical staff, HIV peer support group coordinators and counsellors	5
Service providers total		5

3.5.4 Data collection

Methods of data collection included individual IDIs with ALHIV, drawings of their imagination of the HIV-virus as a visual method, follow-up IDIs after 2-4 weeks, as well as FGDs with ALHIV and service providers. This triangulation of data collection methods was chosen to gain a deeper insight into the phenomena explored. The data were collected face-to-face at an agreed time, mostly during the weekends to avoid interfering with participants’ school schedules. As the IDIs and FGDs with ALHIV were conducted in Chichewa, the inclusion of two translators was required. Verbal accounts of the service providers were collected in the English language.

All interviews and FGDs were undertaken within the HIV clinic setting in a quiet room to avoid disturbances. The IDIs and FGDs with ALHIV were conducted by the researcher and simultaneously translated into Chichewa by two identified staff members employed at the HIV clinic, who were known by the participants. To ensure compliance with confidentiality, the translators signed the Interpreter Confidentiality Form (Appendix 25). The collection of textual

and visual data took place from September 2021 to December 2021 as highlighted in the research timeline (Appendix 33) and was undertaken in four phases. Table 3.5. outlines the data collection process, including the methods used in each phase with their purposes.

Table 3.5.

Phases of data collection

Phase	Data collection method	Purpose
Phase 1	Initial IDI with ALHIV ALHIV’s drawing of the HIV-virus and comparison of participants’ visual products with electron microscopic images of HIV	- To explore the lived experiences and perceptions of ALHIV - To investigate ALHIV’s imagination of the HIV-virus - For participants to reflect on their HIV perceptions
Phase 2	Follow-up IDI with ALHIV	- To review ALHIV’s experience of drawing and whether the observation of the electron microscopic images of the HIV-virus and the reflection on it conveyed changes in their perception of HIV - To link their perception with the language used for HIV - To confirm interpretations made during the initial IDI (member checking)
Phase 3	Four FGDs with ALHIV (divided according to age and gender)	- To discuss ALHIV’s visual products and their underlying meanings - To evaluate alternative images of HIV (electron microscopic images and HIV representations in hospital HIV books)
Phase 4	One FGD with service providers (Clinical staff, HIV peer support group coordinators and counsellors)	- To elucidate on and contextualise the interpretations of service providers on ALHIV’s visual products in comparison to electron microscopic images of HIV and the visual aids used during HIV counselling sessions - To suggest changes on HIV education material

Phase 1

In-depth interviews were conducted with ALHIV as this method is suitable for exploring sensitive topics, such as HIV. Furthermore, through IDIs, participants were able to share their personal experiences, perceptions and beliefs, providing detailed insights into their world. The

initial IDI with ALHIV was conducted to explore their lived experiences and perceptions regarding HIV. Furthermore, participants produced a drawing of the HIV-virus to investigate their imagination of the HIV-virus. Subsequently, participants compared their drawing to electron microscopic images of HIV to reflect on their HIV perceptions.

The most effective method for establishing the meanings of participants' accounts in phenomenological studies are interviews (Laverty, 2003; Wimpenny & Gass, 2000). Semi-structured IDIs were preferred over structured and unstructured IDIs since the rigid, standardised structure of solely using predetermined questions in structured IDIs might have omitted the emergence of central themes (Denzin & Lincoln, 2008). Conducting unstructured IDIs on the other hand as a more spontaneous form of questioning, could have evoked challenges for comparing responses during data analysis (Bogdan & Biklen, 1998). Although more time intensive than structured IDIs, the implementation of semi-structured IDIs is recommended for phenomenological studies since they permit the flexibility of incorporating additional emerging questions to the predetermined inquiries, but still enable the comparison of participants' responses. Follow-up questions to expand and clarify on participants' responses enhanced the richness of data (Van Manen, 2016). Because closed questions disable an in-depth inquiry, open-ended questions were used to offer the participants a space to create their own answer (Smith & Osborn, 2003). Therefore, the use of semi-structured interview guides involved predetermined, open-ended questions, allowing the participants to communicate their experiences without restrictions and in their own words. Prior to data collection, the topic guides were reviewed and evaluated with the translators to ensure their feasibility and to be certain that the meanings would not be lost in translation (Creswell & Creswell, 2017). All interview topic guides (Appendices 26, 28, 30), except the one for the FGD with the service providers (Appendix 34), were translated into Chichewa (Appendices 27, 29, 31).

Phase 2

A follow-up IDI with ALHIV after 2-4 weeks from the initial IDI allowed the confirmation of the interpretations of the initial interview (member checking) and included reflective accounts of participants' drawings and whether the observation of the electron microscopic HIV images conveyed changes in their HIV perception. Moreover, HIV representations in hospital HIV books and the local term for HIV "Kachilombo" were discussed and linked to their HIV perceptions. The inclusion of a follow-up IDI generated richer narratives due to the established trust, which allowed the participants to respond more openly in the second IDI.

Phase 3

The four FGDs involved the same ALHIV, who participated in both IDIs, however, for the FGDs the participants were divided according to gender and age (Table 3.2.), allowing them to relax and talk more freely about sensitive HIV-related themes. This generated a broader scope of information through the participants' interaction (Creswell & Creswell, 2017) and thus, similarities and differences of their lived experiences and perceptions, as well as of their underlying meanings, could be exposed and discussed. With the participants' permission to show and discuss their drawings during the FGDs, ALHIV further elaborated on the visual products and accounts obtained through the IDIs (Creswell & Creswell, 2017). Furthermore, the groups evaluated alternative HIV images, including electron microscopic HIV images and HIV representations in hospital HIV books.

Phase 4

Timing the FGD with the service providers as a final data collection point provided another layer of interpretation of ALHIV's verbal and pictorial accounts, but also highlighted potential improvements regarding HIV-related educational approaches. Since they were in frequent personal contact with ALHIV, their experiences offered valuable insights into their understanding of the phenomena. This group also assessed alternative HIV images, including electron microscopic HIV images and HIV representations in hospital HIV books. Additionally, field notes, such as telephone conversations or meetings with hospital staff were documented, ensuring the participants' details were kept confidential. With the permission of the participants, IDIs and FGDs were audio-recorded, translated and transcripts were then produced.

3.5.5 Arts-based research

The therapeutic value of art has been widely acknowledged, however, as a method of inquiry in health research, using art is still relatively novel (Wang et al., 2017). Arts-based research (ABR) refers to the endeavours to reveal meanings in artistic ways, which might be unintelligible by the means of restricted verbal communication (Barone & Eisner, 2012). Methodologically, ABR has the potential for unfolding often disregarded viewpoints and generating knowledge in different disciplines, including psychology and educational, social and health sciences (Leavy, 2020). Qualitative research employs diverse ABR methods, such as visual art, literacy art and performance art (Fraser & Al Sayah, 2011; Wang et al., 2017).

Visual ABR methods as representations of participants' voices apply drawings (Boydell et al., 2015; Broadbent et al., 2004), photography (Coemans et al., 2019; Hanna & Jacobs, 1993; Wang & Hannes, 2014) and comics (Kuttner et al., 2021; Toroyan & Reddy, 1997) among other methods to elicit perceptions, experiences or emotions. These methods are largely

participant driven and as a result of visualising their inner world, participants often feel empowered (Blaisdell et al., 2019; Oliffe et al., 2008). While ABR methods can be used on their own, often a triangulation with other qualitative research methods, such as IDIs or FGDs, is conducted (Van der Vaart et al., 2018). Nevertheless, in their systematic review on ABR methods in health research, Fraser and Al Sayah (2011) pointed out that the included studies lacked justification for employing ABR methods. Furthermore, ethical considerations, such as regarding data ownership and participants' anonymity were insufficiently taken into account.

Drawing as a research method

Drawing as an ABR method appeared to be beneficial in research exploring sensitive and emotive topics, such as cancer (Bendelow et al., 1996) and death (Vlok & de Witt, 2012). Also in HIV research, drawings have contributed to an enhanced understanding of various phenomena, including HIV-related stigma (Campbell et al., 2010), experiences and knowledge about HIV (Becker-Zayas et al., 2018; Campbell et al., 2015) and HIV perceptions among Tanzanian teachers (Wood et al., 2013). Drawings were also an effective data source for gaining insight into how the experiences of South African ALHIV influence their identity (Pienaar & Visser, 2012) and for investigating undiscussed HIV perceptions among Ugandan students (Mutonyi & Kendrick, 2011).

By employing drawing as research method, this study not only empowered the participants through active engagement in the research (Clacherty & Donald, 2007; Coad, 2007), but also provided data in form of produced drawings, adding to the depth of the interview process, as the visual products generated knowledge and concurrently served as a medium of communication (Fraser & Al Sayah, 2011). To further investigate the meanings of the participants' drawings, IDIs and FGDs were used as recommended by Driessnack (2006). The combination of drawing with an oral component helped the participants to expound the meaning attached to their drawings, which was important to avoid misinterpretations of the visual products (Barker & Weller, 2003; Vanner & Kimani, 2017). Furthermore, the drawings allowed the exploration of ALHIV's imaginative worlds and access to their experiences and perceptions regarding HIV from a different perspective. Moreover, the drawing activity supported participants in reflecting on their lived experiences and perceptions, and by using this non-verbal form of expression, helped ALHIV, who had challenges in articulation (Fraser & Al Sayah, 2011). Enabling the participants to illuminate their imaginations and perceptions of HIV through the visual, in addition to the verbal expressions, elucidated their perceptions, experiences, attitudes and behaviours (Cheung et al., 2016). The use of solely verbal data collection methods may have provided a limited insight into the phenomenon due to HIV's stigmatising nature and the associated silence and secrecy surrounding this topic. Since

practically, making art by itself can reduce stress levels, this approach was deemed to fit perfectly for researching HIV as a sensitive, stress-inducing topic (WHO, 2022c). Also in other phenomenological studies, drawings were used to enrich the interpretation of data (Boden & Eatough, 2014; Boden et al., 2019; Cohen-Miller, 2018).

Integrating drawings into phenomenology

According to Heidegger (1962, p.58) phenomenology refers to “letting what shows itself to be seen from itself, just as it shows from itself.” Despite the importance of language to unfold meaning, drawings have an equal potential to show individuals’ understanding of reality. Moreover, drawing can act as medium to decrypt, translate and show meanings in visual form of individuals’ perceptions and lived experiences. In this study the participants’ drawings were envisioned as an environmental instrument to recall and engender their past memories and present their perceptions of HIV (Fernandes et al., 2018; Meade et al., 2018).

Drawings provide an additional medium to access an understanding of meanings, specifically when investigating complex phenomena that are difficult to articulate (Visse et al., 2019). In consideration of the ontologically unique meanings of drawings, they are strongly embedded within the artists’ cultural context and by the artistic creation itself, perceptions are transformed and born into the phenomenality of existence (Crowther, 2017). Thus, by drawing HIV, the participants were able to share their realities on how they imagine the HIV-virus to look like in their bodies. By reference to their visual products, they were further able to construct and translate this visual information for explaining their perceptions of HIV’s intentions and aptitudes within their bodies. In agreement with Heidegger (1962), Merleau-Ponty (2004) points out that reality is conditioned by social constructs, however, Merleau-Ponty discourses on the body in connection with existing in the world. In this regard, the generation of artwork, including drawings, allows the recreation of reality with its phenomena translated into the visible world. Understanding the theoretical affinity between phenomenology and drawing as an ABR method is of pertinence for this study since through the underpinning relativist ontology, the use of drawings has the potential for gaining visible insights into ALHIV’s world of HIV perceptions. Furthermore, drawing as an ABR method aligns with the SCT since participants’ visual perceptions and understanding of HIV were shaped through the environmental, personal and behavioural domains of the SCT as previously discussed.

3.5.6 Data management and analysis

Data management

In line with the approval by the research ethics committee at Lancaster University and the National Committee on Research in the Social Sciences and Humanities in Malawi, the IDIs and FGDs were audio recorded with the permission of the research participants. Directly after the IDIs and FGDs, the audio recordings were transferred to the researcher's encrypted and password protected laptop, uploaded digitally onto the Lancaster University's secure storage system (OneDrive) and then deleted from the audio recorder. Additionally, the signed assent forms, consent forms and the interpreter confidentiality forms were stored digitally on OneDrive. Once the audio data had been transcribed by the researcher, the audio files were deleted from the researcher's laptop and the transcripts were, together with scans of the visual products, uploaded onto OneDrive. The original drawings and signed assent, consent and interpreter confidentiality forms are stored securely with the principal investigator for 10 years and will then be destroyed. To comply with the General Data Protection Regulation, pseudonyms were used on the transcripts to ensure anonymity.

Data analysis

Qualitative data analysis involves methods aimed at the identification and categorisation of emerging themes from qualitative data. Notwithstanding its flexibility, qualitative data analysis comprises eclectic processes to convert the collected data, such as word-based data from transcripts into a narrative, answering a research question (Bazeley, 2020). From an epistemological subjectivist stance, the interpretation of identified themes considered the discernment of the disguised meanings of participants' perceptions. The analysis of data commenced during the data collection period, while the participants described and interpreted the meanings of their perceptions and experiences regarding HIV, driven by their drawings and questions from the topic guides (Appendices 26-32). The follow-up IDI and FGDs were used to clarify on unclear responses acknowledged from the first IDI (member checking) to avoid misinterpretations that could have affected the data analysis. After the audio recordings were transcribed verbatim, the researcher verified the transcripts to ensure their quality and accuracy. Subsequently, the transcripts and notes made during the data collection process were manually analysed without using data analysis software.

Reflexive thematic analysis (TA) was used for data analysis following an inductive, idiographic and iterative approach, including the identification and grouping of themes at a latent level of interpretation to arrive at concluding themes, which were then translated into a narrative account (Braun & Clarke, 2019). TA allows the combination of multiple data sources, such as transcripts of IDIs, FGDs and visual images. Furthermore, TA is congruent with the research

aims and is appropriate for the application to hermeneutic phenomenological studies in order to provide an in-depth understanding of a phenomenon (Van Manen, 2016).

Braun and Clarke's (2006) six recommended steps of familiarisation, coding, theme generation, theme review, theme definition and written narrative were followed for the reflexive TA. First, the transcripts were repeatedly read, including the notes written during IDIs, FGDs and the reflective journal to become immersed and acquainted with the data (Bryman, 2016). Initial thoughts, based on the topic guides, were recorded for each transcript. Coding to narrow down the data was performed by identification of emergent codes in the transcripts to organise and structure the data with regard to the research question. Therefore, important sections within the transcripts were highlighted, culminating in the creation of a codebook for identifying and categorising patterns, concepts, relevant themes and links between them. Codes that revealed a connection, shaped the base for the theme generation. An example of a transcript with initial codes is outlined at Appendix 34. Step three entailed the generation of themes and subthemes emerging from the codes identified in step two. By comparing the themes, patterns and parallels, inconsistencies were acknowledged which were reflected and elaborated on with the participants during the FGDs. This allowed the rectification of misinterpretations that could have compromised the data analysis. Step four of TA included reviewing, refining, modifying and categorising the identified themes to obtain a correct reflection of the data. To improve the coherence and applicability of the themes, codes were further reorganised, included or withdrawn. The purpose of step five is the definition of themes and subthemes with their interrelations. Thus, the final themes were decided upon agreement with the supervisory team and were then utilised for the reporting of the findings. Designated verbatim quotes were chosen to illustrate and represent the identified themes, supported by participants' visual products. The final step of TA entailed a written narrative of the data analysis, which is presented in the findings chapter, where the identified three main themes and 13 subthemes are discussed with their interpretation in the context of Bandura's SCT and existing literature.

The drawings, enhancing the data analysis process by conveying meaning in non-verbal visual voices, were contextualised by the participants' narratives, which added meaning to their visual products by verbalising their own reflections and interpretations during the IDIs and FGDs (Arruda, 2015). This helped to reduce interpretation bias, since the interpretations of the visual products remained close to the meaning participants attached to them (Neusar, 2014). However, drawings can be analysed in consideration of the artist (creation of the drawing), the drawings themselves and the researcher's perceptions of the drawings (Mitchell et al., 2011; Rose, 2016). Evaluating the visual products in light of these levels may expose inconsistencies between visual and verbal expressions (Martikainen, 2019).

3.6 Ethical considerations

The research followed the ethical principles of the Declaration of Helsinki (World Medical Association, 2022). After receiving the permission to conduct the study from the research setting, approval from Lancaster University Faculty of Health and Medicine Research Ethics Committee and the National Commission for Science and Technology in Malawi was sought and approved (Appendices 6, 8). The amendment regarding the change of the research setting and the additional recruitment strategy was granted by both research ethics committees (Appendices 7, 9, 10). Since ALHIV were the main participants in this study, the process of informed consent adhered diligently to the ethical principles of autonomy, non-maleficence, beneficence and justice (Alderson & Morrow, 2004). To ensure that participation was entirely voluntary and not coercive, prospective participants received adequate information on the research process, the benefits and possible risks or anticipated discomforts, the support provided in case of distress and the right to withdraw their consent without any negative consequences (Bekker et al., 2014).

This information, including resources in case of distress, was explained verbally to all participants and caregivers, but was also incorporated in written form in the PIS. Furthermore, the information for ALHIV and their caregivers was conveyed in simple terms, using their local language to assure comprehension. The adolescents and their caregivers, as well as the service providers had at least 48 hours before deciding to enrol in the study and the opportunity to ask questions before signing the assent/consent form. In addition, the PISs and the assent and consent form for ALHIV and their caregivers was translated into the local language. For ALHIV aged below 18 years, both, the caregivers and the adolescents were required to sign the assent/consent form with the possibility to withdraw their consent at any time until four weeks after completing data collection and without giving a reason for withdrawal. However, none of the participants withdrew their consent. As the ALHIV participated at the peer support group without their caregivers, also during their study participation the caregivers were not obliged to be present, but they could agree on their preference.

For participants, who were under 18 years old, the assent/consent process entailed clear and sufficient information to ensure the participants understood the research and what it meant to participate. By doing that, the participants felt involved in the study, but could make the decision to withdraw. This was important considering the sensitive topic of HIV and the associated stigma and discrimination. Furthermore, a meeting with caregivers and ALHIV aged below 18 years was arranged to discuss the PIS, answer questions and for them to sign the assent and consent forms. The consent included the permission to record the interviews and to use their data. To avoid ethical challenges regarding confidentiality and privacy, the participants did not

use their names on their drawings (Pink, 2004). The drawings were coded to the code of the interview to link these. To avoid influencing the participants' decision on participation, the recruitment process was led by peer support group coordinators, who emphasised that participation was entirely voluntary and that the decision had no influence on the care they are receiving. To ensure voluntary participation, instead of monetary incentives, the participants received transport reimbursements and refreshments.

Distress during data collection

Given that the sensitive topic of HIV was discussed, this could have elicited psychological distress in the participants. Therefore, the presence of a same sex peer support group coordinator as translator, helped in monitoring the impact of the interview. For the case of participants experiencing emotional discomfort, the interview would have been paused in the first instance and the participants would have been asked whether they wanted to continue; additional support services would have been suggested, as appropriate. However, none of the participants showed signs of distress requiring any form of intervention. They were further encouraged to seek support from their caregivers or the organisations identified in the PIS.

The duration of an interview was expected to take about 60 minutes, but if it went on longer, participants were offered the opportunity to take a break. In addition, it was crucial for the researcher to be non-judgemental about the quality of the drawings and the participants needed reassurance that the emphasis of the drawing lied solely on the content. None of the participants wanted to retain their drawings, but if they would have wanted to keep their visual product, they would have received their drawings after the researcher had produced a scan of them.

Confidentiality and anonymity

Because the topic of HIV is highly associated with stigma, anonymity and confidentiality were crucial. Participants received information on how their data were anonymised and stored to maintain their privacy. Confidentiality and anonymity applied to recorded, written and visual data. With the use of pseudonyms, the participants' privacy and identity were always protected. However, the participants were informed about limits of confidentiality, such as the researcher's inability to control the disclosure of FGD participants after the study or in the case of risk or harm, which would have obliged the researcher to involve a staff member. These incidents did not occur but would have been reported to the supervisory team.

3.7 Trustworthiness and rigour of the research

This qualitative study employed Lincoln and Guba's (1986) assessment criteria for research trustworthiness and rigour, including credibility, transferability, dependability and confirmability. Credibility refers to the assurance of presenting accurate findings that are congruent with the participants' accounts and realities (Maher et al., 2018). This was achieved through a consistent and transparent methodological approach, and the inclusion of member checking to confirm the interpretations (Guba & Lincoln, 1994). Transferability denotes to which degree the findings might be judged valid for other populations or contexts (Guest et al., 2012). This was supported through transparency in all phases of the research design, so that decisions made were intelligible, consistent and reproducible (Connelly, 2016). Additionally, the purposive sampling method and thick descriptions of the study context, the setting and the included research participants enhanced the findings' transferability (Creswell & Poth, 2016). Qualitative studies aim to attain dependability, which is defined as the extent to which the research documentation allows auditing, critiquing and repeating the study, receiving consistent results (Priest, 2006; Sandelowski, 1993). By the employment of an audit trail, a detailed description of the investigator's role, as well as of data collection and analysis procedures, dependability was established (Bowling, 2014). Confirmability is defined as the research findings' objectivity, that, irrespective of the researcher's influence, reflects and confirms the participants' views. This was addressed by the researcher's reflexivity and the implementation of an audit trail (Lincoln & Guba, 1986). Considering the emic stance of the researcher and the subjective nature of hermeneutic phenomenological studies through their interpretive character, the researcher's continuous reflexivity to acknowledge the direct influences on the study has been recorded in a reflective journal (Bryant, 2009).

3.8 Conclusion

In line with a constructivist worldview, a relativist ontology and subjectivist epistemology, this qualitative study employed hermeneutic phenomenology and reflexive TA. To understand the ways ALHIV imagine the HIV-virus and how these images and the language used for HIV impact on their emotional wellbeing, perceptions and lived experiences, Bandura's SCT was used. Data were collected through semi-structured IDIs, FGDs and drawings. Participants were sampled purposively and included 16 ALHIV attending a peer support group in a Lilongwe-based clinic and five service providers working at this clinic. The next chapter will outline the findings of this research.

CHAPTER 4: FINDINGS

4.1 Introduction

This chapter explains the findings of the IDIs, FGDs and the drawings, which are organised according to the main themes identified following the reflexive TA. Data was analysed manually without using data analysis software and the following three main themes were identified: characteristics of HIV, language used for HIV and learning about HIV (Table 4.1.). These themes elucidate similarities and differences of how ALHIV describe, perceive and imagine the HIV-virus in their bodies, as well as how these interpretations influence their emotional wellbeing. In addition, the views of service providers on these themes are illuminated.

Table 4.1.

Main themes and subthemes

Main themes	Subthemes
Characteristics of HIV	HIV portrayed as human being HIV portrayed as an insect HIV portrayed as an animal HIV portrayed as a fluid
The language used for HIV	The language of silence and secrecy Local HIV term “Kachilombo” War metaphors for HIV
Understanding HIV	Community understanding of HIV Lessons about HIV at schools Information about HIV at hospitals HIV books used in hospitals HIV under the electron microscope Emotional responses

4.2 Characteristics of HIV

The ways how ALHIV imagined the HIV-virus to look and act within their bodies had been challenging to grasp using solely verbal descriptions of their imaginations. Therefore, as argued in the methodology chapter, encouraging the participants to draw their imagination of HIV was a valuable tool, enabling them to express their realities in a visual form and additionally conveying their meanings verbally. Noticeably, the participants’ visual products presented a mirror into ALHIV’s HIV imaginations and thus, permitted a deeper insight into their realities, which enhanced the comprehension of their HIV perceptions.

Generally, ALHIV described HIV as an organism with gender identity and nutritional needs to function. While the majority of participants drew HIV as an animal or insect, some portrayed it in form of a human being, existing and “fighting” within their bodies. Furthermore, HIV was drawn with features, such as a face with eyes, nose, ears, mouth and teeth, a body, feet and arms. Hence, HIV has been anticipated existing with functional senses, including sight, taste, smell and hearing. Intriguingly, for some participants HIV was able to communicate with other HIV-viruses or CD4 cells in their body. Those perceptions were related to their understanding of HIV requiring to adapt to, function and move in a habitat, which in this case is the human body. Regarding ALHIV’s imagination of the size of HIV, most understood the concept of an invisible pathogen within their body, and as such, for them HIV was invisible. However, some participants thought that HIV might be visible, having a size from 1-14cm. The sizes of their drawings ranged from 0.5 x 1.3cm to 10 x 14cm. Moreover, most participants imagined HIV in red colour due to its habitation in blood, others believed it would be black, transparent, grey or white. The following sections illustrate the participants’ individual imaginations of HIV with their drawings. For all participants it was the first time visualising their imagination of the HIV-virus on paper.

4.2.1 HIV portrayed as human being

Lion lived with both of his parents and his older sister, who were all aware of his HIV status. At age 11, he was told by a healthcare worker at the hospital that he was HIV-positive; although he felt it was important to understand how he acquired HIV, he did not know. He described his drawing of HIV as an unfriendly virus, because “...it disturbs our body” (Lion, male, 13).



(Lion, male, 13)

Lion believed that there were 30 visible female and male HIV-viruses in his body, of which he produced a very colourful drawing, despite he imagined HIV to be transparent without colour.

He perceived HIV to be younger than himself and with the ability to see, breathe, hear, and smell in his body. However, he was sceptical about HIV's ability to eat and drink and unsure of where the HIV-virus could be found, but he described it to be moving fast through his body with poor ART adherence, and standing still with good ART adherence. This perception of HIV moving was similar to those of other participants, who imagined HIV travelling within the body or fighting and destroying either CD4 cells or the participants' body. Participants also explained that HIV's fighting ability depended on ART adherence and thus, adherence was understood as protection against HIV attacking their body due to ART's power to make HIV "weak" or "asleep".

Nevertheless, Lion explained that he always imagined HIV as he had depicted it on his drawing and that HIV illustrated in a hospital book had influenced his imagination. During the drawing process Lion felt positive, but his emotions turned negative when looking at the completed visual product, which he explained as follows:

*"Because it's HIV,...I always think how HIV enters my body....
Because the virus want to affect my body."* (Lion, male, 13)

Interestingly, although he understood ART as lifelong treatment, he believed that if he adheres well, HIV would disappear one day.

In comparison, Anne was diagnosed and got to know her HIV status at age 13 due to a Herpes Zoster infection. Because her mother told her about the diagnosis and kept an open dialogue about her own HIV infection prior to Anne's diagnosis, Anne was able to accept her HIV status. Also meeting other adolescents in the same situation at a support group helped her in coping with the chronic condition. For Anne, HIV appeared scary in her imagination.



(Anne, female, 18)

She estimated that she had 1,000 HIV-viruses in her body and perceived HIV as an invisible, transparent organism without gender, who lived in the red blood cells, “swimming” fast through her blood. Anne imagined HIV’s face with two eyes to be able to see, a nose for breathing and a mouth with sharp teeth used for “biting the body” if ART had not been taken.

In addition, she believed that HIV was not eating, communicating, hearing or smelling, but was able to fight and “destroy the body” with its long, sharp claws on the toes of each foot. For protection, HIV had “black shells” at the side of its head. Regarding HIV’s age, Anne thought that HIV had the same age as herself, because she was born with it. Interestingly, some participants had different perceptions regarding the age of HIV in their body, imagining HIV to be younger or older than themselves, since the virus was present before their birth. Nevertheless, Anne’s HIV perception was shaped by the local term used for HIV “Kachilombo”. Her feelings during the drawing were very positive, however, when evaluating her final visual product, she found it scary, especially due to HIV’s sharp teeth and claws.

For Shanita, who lived with her mother and two older brothers, HIV in her body looked like a person:



(Shanita, female, 14)

She drew HIV to the size she imagined HIV to be in her body (3 x 1.5cm), with a shirt and skirt, consisting of blue water. For HIV to be able to move in her body, it used the arms and feet. She described HIV swimming slowly “like a fish” in her intestines, where it resided. This perception corresponded with the belief of most participants, who thought HIV swims in the blood, however, for others, HIV was walking with the legs or crawling like an insect. While the majority imagined HIV moving with a high speed, a few assumed it to move slowly.

Shanita believed that the HIV-viruses were younger than herself and that there were six HIV-viruses, three male and three female, who all looked the same. Fascinatingly, also other respondents perceived HIV to have a gender identity, either male or female, with the purpose of multiplication. While for most participants female and male viruses resembled each other, some thought that there were gender differences, such as female or male HIV-viruses being bigger in size. Additionally, Shanita imagined HIV to have a face without ears, appearing friendly at first sight, but upon further questioning her image of HIV's toothless, smiling mouth, she explained HIV had a vicious smile:

“It is smiling, because it wants to destroy the body.” (Shanita, female, 14)

She perceived HIV with a nose to smell blood, eyes to investigate the location of blood in her body and a mouth to drink blood, aiming to destroy her body. However, her feeling towards the drawing was pleasant, as she drew a friendly version of her HIV imagination. Regarding the source of her imagination, she explained that she was influenced by a hospital book, in which HIV was illustrated in a dangerous way. Equally to Shanita, Chisomo, who lived with her mother and two younger siblings, was inspired by a hospital HIV book. The similarities between the images portrayed by Chisomo and Shanita include the imagined HIV to take on a human form with a face and the blood as residence through which it floats through the body:



(Chisomo, female, 15)

However, for Chisomo, HIV had an invisible size and she believed that in her body a single HIV-virus was present, which obtained the same food and drinks she takes in. Remarkably, derivated from human behaviour, for HIV to survive and live, other participants also anthropomorphised HIV in that they understood it needed to be fed. They believed HIV required the same nourishment as themselves or it needed to feed on liver or blood. Therefore, HIV was considered having a mouth, teeth, scissors or a trunk. Nevertheless, Chisomo was

unsure about the age of this HIV-virus and regarding its gender, in the first IDI she explained that it would be a male virus due to the absence of hair and a nose. Surprisingly, in the follow-up IDI she modified this statement and clarified that women carry a female virus while men had a male virus in their body. For her, HIV required two eyes to see the CD4 cells, which she perceived as HIV's "enemies", and a mouth with teeth, which served as decoration. However, her HIV appeared without a nose and ears, therefore it was unable to hear, breathe or smell. Intriguingly, while Shanita's HIV was silent, Chisomo shared her experience of being able to actually hear the HIV-virus making a sound, which she expressed as stomach growling, occurring once to twice daily, especially when she feels hungry. She interpreted this sound as "HIV being hungry", because it stopped when she ate and took ART. Her feelings towards her drawing were positive as her visual product depicted HIV when she was adhering to ART. Interestingly, she reported that during the process of drawing, she felt good, because she experienced a sense of HIV escaping from her body. However, she added that after five days, she realised that the HIV-virus was still in her.

4.2.2 HIV portrayed as an insect

While some participants were unsure about HIV's location in their body, for others HIV resided in the stomach, intestines, the back, the lung, the gallbladder or in the blood. Thus, many participants illustrated HIV in red colour. This was also true for Lydia, who, after receiving the HIV diagnosis by hospital staff at age 12, faced no challenges accepting her HIV status due to the prior HIV information she received at school and her mother's explanation that she acquired HIV through mother-to-child transmission. Lydia illustrated HIV as a red ant with four legs, living and swimming in the blood:



(Lydia, female, 13)

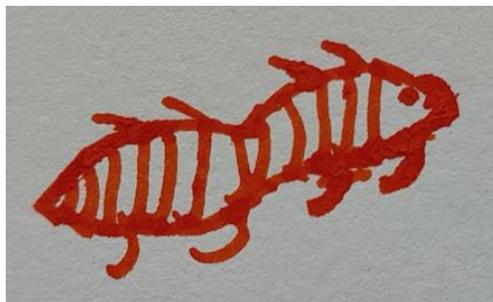
She imagined HIV to be invisible and soundless with both genders for multiplication. For her, the males were larger in size compared to the female HIV-viruses. Regarding HIV's age, she explained it to have the same age and life expectancy as herself. While Lydia stated in the first IDI to have 50 HIV-viruses, decreasing with good ART adherence, in the follow-up IDI she explained that with good ART adherence there would be only one weak HIV-virus sleeping in

her body. Furthermore, her HIV had a face with two eyes to see the CD4 cells, a nose to breathe and ears to hear the CD4 cells' location. However, HIV was only able to hear the CD4 cells when ART was not taken, as then the virus would be awake. Moreover, HIV had a toothless mouth to suck blood and two sharp trunks on the forehead to fight the CD4 cells when nonadherent to ART. Similarly, other participants concurred that HIV was performing a fight within their bodies, using features, such as a trunk, beak, scissors, a shell or sharp claws. Consistent with Chisomo's perception, Lydia also believed that HIV ate the same food as herself:

"The same as we eat. When we are taking medication the virus is very weak, so it can't eat."

(Lydia, female, 13)

Her imagination of HIV was also guided by a hospital HIV book. Lydia's feelings towards the drawing process and the visual product itself were positive, providing relief. Her drawing resembled Mkango's HIV imagination:



(Mkango, male, 12)

For Mkango, HIV was a genderless, red, hairless insect, with a soft, striped body and eight legs to move fast through the blood, where it resided. Its size was very tiny and only visible through a microscope. HIV's face excluded ears, but included two eyes to see, a nose and a mouth, that was used to drink blood, with teeth *"to eat the meat of his body"*. Mkango believed that because there were multiple HIV-viruses in his body, they might have disagreements over food and thus, they might argue with each other:

"Because there are many, not a single virus. They may have some disagreements. Ah, maybe when they are eating something, they may quarrel." (Mkango, male, 12)

Regarding HIV's age, Mkango imagined the HIV-viruses to be younger than himself, however, he was unable to explain this in more detail. Despite visualising HIV in a similar way to Lydia,

Mkango indicated that his HIV imagination was influenced by the local term used for HIV "Kachilombo", which will be discussed in the next section. In contrast to Lydia and Mkango, who imagined HIV in red colour, Daligo believed that HIV in his body was black. Daligo lived with his mother, older brother and aunt, who were all aware of his HIV status. As his brother and both of his parents were also taking ART, he knew that he was not alone with this lifelong commitment. His mother informed him that he acquired HIV through mother-to-child transmission, which he said, was important for him to know. Daligo considered HIV to look like a small, hairless, black weevil, however, he could not tell, where in his body HIV could be found:



(Daligo, male, 18)

He imagined HIV as invisible female and male HIV-viruses, required for multiplication, whereby there were more females that were larger in size. Daligo further illustrated HIV with a face, including two eyes to recognise the CD4 cells' location, a nose to breathe and smell blood, two ears of which he was not sure whether HIV was able to hear with. In addition, his HIV-virus had a mouth to suck blood and sharp teeth to bite, nevertheless, his HIV was unable to make a sound or communicate. Furthermore, he described HIV with four ant-like legs, which were used to crawl fast whenever ART was not taken, yet HIV was not moving under ART, when it was sleeping. Regarding the number of HIV-viruses in his body, Daligo estimated that he had around 100,000 viruses in his body, however, he was unable to evaluate if this number of viruses would be "good" or "bad" for his health, but he indicated that the number of HIV-viruses would be irrelevant, as for him it was more crucial to accept any number of HIV-viruses in his body. Daligo perceived HIV to be nine years younger than himself with a life expectancy of 15-16 years. Interestingly, he believed that, as HIV was aging, its size would grow larger over time. Also he stated that his imagination of HIV originated from hospital HIV books.

4.2.3 HIV portrayed as an animal

Similar to HIV being visualised as a human being or insect, the idea of HIV as an animal was presented. Mishello lived with both of his parents and three siblings, who were all aware of his HIV status. His parents and one sister were also on ART, which he knew was a lifelong treatment. For Mishello, HIV looked like a tiny, invisible, furry, red animal, which resided in his chest and lungs. He believed that in his body, there were many HIV-viruses, all males and younger than himself. His first drawing showed a very small HIV-virus, measuring only 1.3 x 0.5cm:



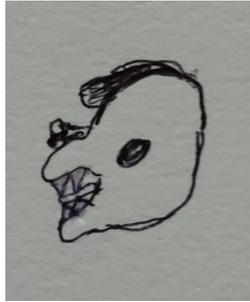
(Mishello, male, 10; drawing enlarged)

Upon requesting a larger drawing of the HIV-virus, he produced the following work:



(Mishello, male, 10)

While on the first drawing HIV was depicted in red, the bigger version of HIV was in a grey colour, which he explained would be HIV's "real" colour in his body. However, he later added that ART would change HIV's colour to green. Furthermore, he stated that HIV moved with two legs, and had three toes with sharp claws, which were used to fight the CD4 cells. Moreover, his HIV also employed the fur as a tool for fighting the CD4 cells. Mishello described the fur as scary in appearance and therefore, HIV used it to scare away the CD4 cells. He then continued drawing a more detailed version of HIV's face:



(Mishello, male, 10)

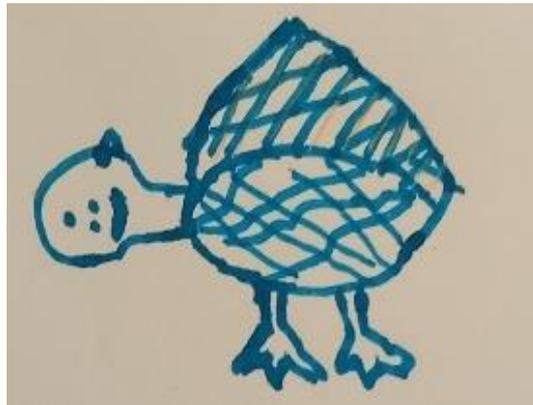
On this drawing, Mishello illustrated HIV's face with one eye, which it requires to see its location, a nose for breathing and smelling the CD4 cells and a black, soft beak located on the bridge of the nose. Despite the absence of ears, Mishello believed that the HIV-viruses were able to hear disagreements between the CD4 cells. He also envisaged HIV making sound, which he described as the following noise:

"Like when you are walking, when you are wearing shoes, that sound." (Mishello, male, 10)

HIV's mouth with accommodating sharp, white teeth was used for "eating" blood and for biting his chest, when he forgot to take his ART. This was what, according to his interpretation, would make him sick frequently. Analogously, other participants believed that ART increased the power of the CD4 cells, for them to be able to fight HIV and to make HIV weak and asleep. On the other hand, participants articulated the negative consequences of ART non-adherence, such as HIV's multiplication and people falling ill. Some participants expressed this in a more visual way through explanations of the HIV-virus increasing in size, or HIV waking up, moving and attacking or destroying the CD4 cells or their body. Furthermore, Mishello believed that his body would look stronger without HIV, which might be due to his previously experienced episodes of ill-health. While in the first IDI he reported that his HIV imagination had been influenced by a hospital HIV book, during the follow-up IDI, he explained that his imagination was guided by the term "Kachilombo". His feelings during the drawing process and towards his visual products were positive.

Yet, while for Mishello HIV's colour was grey or green, other participants portrayed HIV as black, such as Amina, who lived with her father, two siblings and stepmother. Close family members were aware of her HIV status and she understood that she, together with her father and stepmother, had to take ART for life. Regarding the number of HIV-viruses in her body, she explained that with good ART adherence, there would be 9-10 viruses in her body, while the number could increase to 100 if nonadherent to ART. Amina visualised HIV as a turtle,

which, attributed to HIV's tiny size, was invisible to her eyes. However, with poor ART adherence, she believed that HIV would grow in size:



(Amina, female, 16)

Amina's HIV imagination included a hard shell "as protection from other viruses", two legs with three toes each, a neck and a head. The face was depicted without ears, but had two eyes to see its environment, a nose for smelling "the liver in her body" and a mouth with lips and sharp teeth to feed on liver. She believed that HIV resided in her blood, moving fast with the feet to her heart, stomach and lungs if nonadherent to ART. Additionally, she thought that the HIV-viruses were older than herself and that they were unable to communicate. She differentiated female HIV-viruses with a softer skin from males with a rough skin. Influenced by a hospital HIV book and the term "Kachilombo", her imagination changed over time. Amina's feelings during the drawing process were positive, however, looking at the visual product made her sad:

"I am feeling sad, because the virus will always remain in the body and making me busy taking the ART." (Amina, female, 16)

4.2.4 HIV portrayed as a fluid

Only 12 year old Woimba presented the idea of HIV as a pathogen "similar to COVID-19" without a body or face. During an admission at a hospital at age 10, a healthcare worker told him that he had HIV, however, he explained that he would have preferred to know earlier why he was taking medicine daily. He described initial negative feelings, when he got to know his HIV status:

“I was afraid...HIV is not a good disease. The doctor said after disclosure ‘If you are not taking medication properly, then you may suffer from AIDS, where you may have a lot of diseases.’ That was the biggest fear.” (Woimba, male, 12)

Surprisingly, he believed that HIV is a hereditary condition as he stated that his mother transmitted HIV to him:

“It happened that my grandmother is HIV-positive and she transmitted the virus to my mother and my mother transmitted the virus to me.” (Woimba, male, 12)

While Woimba first drew HIV identically to the hospital HIV book:



(Woimba, male, 12)

his second drawing showed, how he imagined HIV through a microscope:



(Woimba, male, 12)

For him, HIV was a shapeless fluid, visible only under a microscope as added in his drawing.

Woimba believed to carry in total ten HIV-viruses in his body, which were male and female for multiplication, when nonadherent to ART. Regarding the number of HIV-viruses in their bodies, participants had conflicting opinions, varying from 1-100,000 HIV-viruses, whereby most participants understood that with good ART adherence the number of HIV-viruses decreases and thus keeps them healthy. Interestingly, while one participant was unsure of how to control the HIV-viruses in his body, other participants understood ART adherence as the best way to control HIV. However, Woimba imagined HIV swimming fast through the blood in his stomach, where it was able to smell the swallowed ART. In his view, HIV had no food requirements, but it was able to destroy his body by fighting the CD4 cells. Regarding HIV's age Woimba believed it to have the same age as himself with a life expectancy of 60 years. Despite his first drawing was inspired by a hospital HIV book, the second drawing of HIV under the microscope was his own imagination. Both his feelings during the drawing process and towards his visual products were positive.

4.3 The language used for HIV

4.3.1 The language of silence and secrecy

During the FGDs, participants inspected all drawings produced during the research and recognised ALHIV's different imaginations and perceptions regarding HIV, which they attributed to the HIV's invisible nature. However, the service providers ascribed the explanations given during hospital counselling sessions and the term "Kachilombo" to participants' drawings and perceptions of HIV, as discussed in the next section. Nevertheless, these HIV drawings reflect on ways ALHIV try to make sense of HIV and what HIV could do to their bodies, yet, differences between the two age groups (10-14 years and 15-18 years) - or between female and male participants - were not identified. As several participants indicated the important role that the term "Kachilombo" played in influencing their HIV imagination, this section is devoted to the language commonly used regarding HIV in this context.

Considering that HIV is a sensitive, highly stigmatised topic, ALHIV were frequently advised by their caregivers not to disclose their HIV status to others. Mkango was told about his HIV status by his mother when he was eight years old. While he found the age appropriate, he was initially worried and felt "*incomplete*". However, to avoid HIV-related stigma, he was advised not to tell anybody about his HIV status:

"My Mom told me that I should not tell anyone [about my HIV status], it's confidential. Only my Mom and I know." (Mkango, male, 12)

This silence around HIV restricted him from questioning further, despite being unaware of how he acquired HIV. Though the majority of participants got to know their HIV status during counselling sessions by healthcare providers, their caregivers strongly advised them to conceal their HIV status to evade discrimination. Consequently, their autonomy for telling others about their HIV status was taken and they felt a need for secrecy and hiding their ART, so that even close family members were often not aware of their HIV status.

This was true for Thalandira, who got told that she was HIV-positive by her mother at age 11. Her two older brothers were both unaware of her HIV status:

“My two brothers don’t know...My mother keeps it [ART] in a hidden place, because sometimes we have visitors at home, so they can maybe see the medication,...I am afraid they could spread the news to others about my HIV status. It can affect me psychologically, because people would point at me ‘Look at that girl! She is on ART’.”

(Thalandira, female, 13)

Similarly, Anne was informed about her HIV status at age 13 by her mother. She lived, together with her two HIV-negative siblings, at her aunt’s house, however, neither the aunt as her caregiver, nor her siblings, were aware of her HIV status:

“The aunt I live with doesn’t know...she is much talkative. I am afraid she may tell neighbours. My brother and sister are not mature enough that they can keep this secret. I am afraid of discrimination.” (Anne, female, 18)

Nevertheless, keeping the HIV status at home secret may impede ALHIV accessing support by family members, such as providing ART reminders. Daligo, who was told about his HIV status by his mother at age 12, indicated the importance of extended family support regarding ART adherence:

“Everyone know [at home]. The mother told them, as sometimes she goes out and these other people can support me as well to take medication.” (Daligo, male, 18)

Still, others expected harsh punishments if they decided to openly discuss their HIV status, such as Shanita, who, unaware of how she acquired HIV, got to know her HIV status at age 10 by her mother. For her, age 10 was too early, and her initial reaction was sadness, leading to two years of self isolation due to the fear of infecting others during “normal” interactions. Her

mother instructed her to remain silent about her HIV status and, as illustrated by the following quote, Shanita even feared domestic violence if she would talk openly about her HIV status:

“I can feel bad about that [reporting HIV status to others] and my Mom can beat me because of that.” (Shanita, female, 14)

The same was real for Mishello, who was told about his HIV status by his mother at age 8, which he believed was too early, as he initially struggled understanding this information. Also, he was unaware of how he became HIV-positive, but expected punishment in the case of telling others about his HIV status:

“They would beat me. My parents told me to go and play and not to talk about my HIV status.” (Mishello, male, 10)

Jonathan, who lived with both of his parents and two sisters, explained the importance of understanding that he acquired HIV from his mother. On his parents’ request, he had not shared his HIV status with anyone, not even his two sisters. He clarified that caregivers may advise reticence not only to protect their children from HIV-related stigma, but equally to avoid others linking his HIV status to the family:

“They may be angry and disappointed, because if people know that I am HIV-positive they may connect my status to the status of my parents.” (Jonathan, male, 15)

Due to the immense fear of discrimination, ALHIV felt the need to keep their HIV status confidential and as a mandatory secret in order to feel safe and protected. Accordingly, Patuma, who got told about her HIV status at age 12 by hospital staff, was advised by her mother that due to HIV-related stigma, she should not reveal her HIV status to others. Consequently, Patuma fears negative emotions due to living with HIV:

“I am afraid that if I tell them [others], they may spread news about my status. They can maybe tell other people that I am HIV-positive. As a result I may feel guilty of my status and not feel good about that.” (Patuma, female, 14)

Identical fears were shared by Elmore, who lived with his mother and older brother. Concerned about negative consequences due to his HIV status, he had not revealed it to his brother or others:

“Because all say HIV can kill a person. If you tell them, they will be mad at you. Because you are HIV-positive and they are HIV-negative....they will start gossiping, talking bad about me.”

(Elmore, male, 15)

Probably HIV-related discrimination was affected by the fear others project around acquiring HIV as stated by Patuma:

“I just feel that maybe other people can be afraid to get infected with the virus. That is why I am not comfortable telling them my status.” (Patuma, female, 14)

Notably, this tremendous need for secrecy even forced ALHIV into hiding their ART. Chisomo, for example, talked about limiting people, who knew about her HIV status and the need of hiding ART, so that others may not suspect her being HIV-positive:

“...the grandmother doesn't know. I take the drugs and I hide it somewhere so that people cannot see....They can be telling other people... That can lead to stigma and discrimination.”

(Chisomo, female, 15)

Also in view of disclosing their HIV status to intimate relationships, the older ALHIV mentioned the need for secrecy as they feared rejection and losing their face due to their HIV-positive identity. Some participants could imagine talking about their HIV status only in serious relationships. Nevertheless, with growing maturity ALHIV need to learn about the responsibility of preventing HIV onward transmission and therefore, strategies to help them with this task might be of great value.

On the other hand, this secrecy regarding their HIV status was perceived as a protection against stigma. Therefore, some participants found the use of secrecy helpful for their mental health, as the absence of fear made them feel free:

“Secrecy helps someone to live without any bad feelings about stigma, because only parents know about the status, it gives a free mind....it is a part of protection.” (Jonathan, male, 15)

Yet, in comparison to other chronic conditions, HIV was viewed differently, as it was closely linked with sex:

“With sugar [diabetes] you can disclose, but with HIV not...So, people always talk much on HIV than on other diseases...It is because most people think that HIV is connected to sex, unprotected sex.” (Daligo, male, 18)

Also a service provider commented on HIV's humiliating nature:

“HIV is more like that disease that is shameful, because it's something that people, when they are discussing, it's always 'HIV and death', like if you have HIV, at the same point you are dying, of which it doesn't go like that.” (Daniel, male, 26)

Some participants were able to ask HIV-related questions at home, such as Lovemore, who was told about his HIV status at age 15 by hospital staff, however he did not know how he acquired HIV:

“The grandmother is involved in home-based care, supporting people with HIV. She has a lot of information about HIV and I can always ask her.” (Lovemore, male, 16)

Unfortunately, this was not the case for other participants, who rarely or never spoke about HIV in their homes. One of them was Lydia, who got told by her mother that she acquired HIV during pregnancy or delivery, however, Lydia never felt comfortable asking her mother HIV-related questions. Also Amina felt it was important to know how she acquired HIV and believed she got it from her mother, who passed away. She had a lot of questions regarding HIV, but never felt able to ask her family:

“Yes, I have so many questions as ‘How come I am the only one [among the siblings] in the family who is taking ART?’ and ‘How come that both of my parents are also infected with the virus?’...I ask myself inside, in my mind. I am not open with my Dad,...I just keep the questions to myself.” (Amina, female, 16)

Frequently, the support group was mentioned as an important support structure, providing a safe environment for asking questions and discussing HIV-related challenges. In addition, ALHIV felt important to meet peers, making living in secrecy at meetings unnecessary:

*“Teen Club [support group] is very helpful, because they teach us how to live positively and have a healthy life. I feel good to meet friends in the same age, who are in the same situation, they have HIV, we encourage each other about how to live positively.”
(Thalandira, female, 13)*

Correspondingly, Anne explained how her attitude towards HIV positively changed through joining a support group:

“Before Teen Club [support group] I had a more negative attitude regarding my HIV status. Here I saw so many kids, who are HIV-positive, that helped me with coping.”

(Anne, female, 18)

These accounts vividly described the participants’ reality concerning HIV-related stigma, with their constant fear of segregation and rejection, in case others may get to know about their HIV status. However, also the term “Kachilombo” may contribute to misperceptions about HIV in Malawi.

4.3.2 Kachilombo

Since the term “Kachilombo” is also used when talking about insects or small animals in Malawi, the participants frequently depicted HIV as such and thus, they explained the different meanings and attributes of “Kachilombo”. While Amina referred to a *“biting, dangerous insect”* when explaining the term “Kachilombo”:

“Kachilombo means different things. It can be an insect that can bite you. Something which is dangerous that can bite people. Kachilombo can affect people or can make people to be sick.” (Amina, female, 16),

for Ndazona, who was told her HIV status by hospital staff just a year ago, “Kachilombo” denoted a *“dangerous animal”*. Her understanding of “Kachilombo” was also reflected in her drawing of HIV, which depicted a mosquito with a trunk for drinking blood:



(Ndazona, female, 16)

As a result of HIV being a highly sensitive and stigma-related taboo topic, the understanding of “Kachilombo” as euphemism for HIV clearly shaped participants’ perceptions and imaginations of HIV, which was also mirrored in Jonathan’s drawing of HIV as a scorpion with scissors:



(Jonathan, male, 15)

Those drawings visibly express how the impact of language translates into participants’ understanding and imagination of HIV as insect or small animal. The participants further explained that they conceive “Kachilombo” as a dangerous, frightening and invisible invader for which no cure was available:

“It is something that is very scary...because there is no cure for it.” (Patuma, female, 14)

Furthermore, for Patuma and other participants using the word “Kachilombo” was perceived as negative and misleading due to the different meanings it carries:

“People use it in a negative way, something that is very scary and dangerous.”

(Patuma, female, 14)

However, despite the availability of ART, which significantly reduces morbidity and mortality, several participants observed that within their communities the word “Kachilombo” was still closely linked to death, as Anne and Mishello described:

“It is called Kachilombo because in the past it has killed so many people.”

(Anne, female, 18)

“It’s bad, a bad name. It brings diseases, then people always die.”

(Mishello, male, 10)

Daligo highlighted that “Kachilombo” was defined as the singular form of HIV, but considering that there were multiple HIV-viruses in the body, this term was incorrect:

“Zilombo is many, but Ka- is one. The word Kachilombo means that there is one...After looking at the photo, it means there are a lot [of viruses in the body].”

(Daligo, male, 18)

Interestingly, Jonathan also saw an advantage in using the equivocation of the term “Kachilombo”, especially in situations where others around should not understand the topic of discussion. The oblique way this term could be used, provided the space for discussing HIV, while maintaining confidentiality, and thus served as a protection against HIV-related discrimination. Yet, participants held different opinions and preferences of whether to use the term HIV or “Kachilombo”. The majority of participants preferred using the term HIV as it has no double meaning, making the topic of discussion clear. However, some participants favoured calling HIV “Kachilombo ka HIV”, refining the term by distinguishing “Kachilombo” as insect or animal from “Kachilombo ka HIV”:

“People have to understand straight that it’s ‘Kachilombo ka HIV’ than to say Kachilombo, because people will think that Kachilombo is not about HIV, it’s something like an insect.”

(Lydia, female, 13)

On the other hand, as discussed in the previous section, because ALHIV grew up with the instructed and perceived need for secrecy concerning their HIV status, they considered possible consequences for using HIV-related terminologies in public, and thus, the term “Kachilombo”, through its double meaning, was also seen as protection against HIV-related discrimination:

“Better to use the word Kachilombo. Because if a person is talking about HIV, other people can think he is HIV [positive].” (Elmore, male, 15, FGD)

Nevertheless, while the term “Kachilombo” was deemed to protect people from HIV-related stigma, conversely, attributable to its double meaning, it was also perceived as reinforcing discrimination. Hence, the negative influence of language on ALHIV’s emotional wellbeing was considered, as affirmed by Anne:

“Better using HIV than Kachilombo. For our culture here in Malawi, ...Kachilombo can give people different ideas and maybe psychological problems as it is something scary and that can destroy life.” (Anne, female, 18)

Correspondingly, Ndazona held the opinion that the term “Kachilombo” causes stress and triggers discrimination:

“...the word Kachilombo has a negative impact, because that word Kachilombo can cause stress to someone and because people think that ‘HIV is a killer!’ ...people think that if you have Kachilombo, you are dead.” (Ndazona, female, 16, FGD)

Also during the FGD with the service providers the term “Kachilombo” and its use for HIV has been explored. In particular, understanding “Kachilombo” as a single HIV-virus, linked to participants’ drawings of a single virus, was considered inaccurate information, especially when communicating the concept of HIV-virus multiplication and viral load:

“Kachilombo as a single virus is confusing because they don’t think that HIV does multiply.” (Daniel, male, 26)

Thus, a possible modification using the plural form of “Kachilombo” was proposed:

“We have to say ‘You have Tizilombo [plural form of “Kachilombo”] in your body’.” (Eveless, female, 32)

ALHIV’s perceptions regarding the use of the term “Kachilombo” and its impact on their HIV imaginations has been acknowledged, however, while not reflected in their drawings, the participants frequently used war metaphors when explaining HIV.

4.3.3 War metaphors for HIV

The participants used language, including war terminology, describing their experiences living with HIV, their HIV imagination and its corresponding impact. For making sense of scientific ideas, both, male and female participants frequently applied metaphors, such as “fighting” and “attacking” of HIV and CD4 cells, to explain the relationships and battles between them. With the absence of a cure for HIV, but with ART, enabling individuals to live a normal life and preventing complications, HIV can be categorised as a chronic condition. When elaborating on

the positive effects of ART on the CD4 cells for winning the battle against HIV, ALHIV commonly used the “fighting” terminology:

“So if you are taking medication, the CD4 will have power to fight the virus and it [HIV] will get weak and sleep. So you cannot get sick if you adhere to medication.” (Lydia, female, 13)

Accordingly, the negative consequences of HIV fighting the CD4 cells when not adhering to ART were explained. Subsequently, participants expressed a form of “destruction” in their bodies, caused by HIV. However, some participants perceived HIV as dangerous to only those not taking ART and as a result of imagining the HIV-virus as destructive, HIV was perceived as dangerous and lethal:

“That time [during disclosure] I heard that HIV is very dangerous. I thought that that’s the end of my life. I feared to get sick and die.” (Ndazona, female, 17)

In addition, the CD4 cells were labelled as HIV’s “enemy” and the comprehension of “HIV as a killer” was presented as follows:

“[HIV has a mouth] to kill the white blood cells in the body.” (Lovemore, male, 16),

The concept of war also emerged when ALHIV consistently described HIV’s aim as “defeating” the CD4 cells, referred to as “soldiers”:

“It [HIV] can hear the conflict between the soldiers. The virus can run away and go and tell other viruses to come.” (Mishello, male, 10)

While especially the younger participants referred to soldiers when talking about CD4 cells, the older participants were acquainted with more sophisticated medical language and the meaning of “CD4 cells”, “viral load”, HIV transmission and prevention. However, these older ALHIV also visualised HIV as insect, animal or human figure. Interestingly, the word “defeat” was also used, when alluding to the effectiveness of ART:

“To take the medicine clear [well], maybe it can defeat the virus.” (Elmore, male, 15)

Those descriptions of HIV, using war metaphors, created an impression of ALHIV living with a constant battle between the HIV-virus and the CD4 cells in their bodies. The utilisation of war metaphors has been adopted from HIV lessons received at school, but also during hospital

counselling sessions. This has been confirmed in the FGD with the service providers, who explained ALHIV's linguistic presentation of "HIV as a killer" as a metaphorical product of what they learnt about HIV, especially at school, where outdated information would be used for teaching, ignoring the fact that ART enabled people to live a "normal" life with HIV:

"We learnt at school and the teacher told us that 'If you have HIV, you are dead! HIV is a killer!'" (Steve, male, 41)

Also, the use of fear-based messages provided in the hospital to impart HIV-related knowledge and reinforce expected behaviours regarding ART adherence, might contribute to ALHIV's negative perception of HIV:

"Especially that time we say 'If you take your medicines very well, HIV will be sleeping in the body.' That comes to 'If I don't take the medicine, it may wake up and start destroying my body.' So they may see the fighting as something that is a real fight, an animal against them."
(Steve, male, 41)

Service providers further understood the negative impact of threatening messages communicated in HIV education, however, they also believed that downplaying HIV as harmless might cause non-compliance to life-saving treatment. Clearly, the discrepancy between understanding HIV as a "friendly companion" enhancing the emotional wellbeing and the concept of HIV as a destructive "killer" has been illuminated. With the availability of ART as life-saving treatment which allows people to live with HIV as a chronic condition, the importance of what people learn about HIV and how this knowledge is imparted, needs to be considered, as it affects ALHIV's perception about HIV in their body, but also their sense of an "HIV-positive" identity.

4.4 Understanding HIV

In order to accurately understand HIV infection as a chronic condition, caused by a virus, which can be transmitted in various ways - including mother-to-child transmission - ALHIV need to be told their HIV status at an appropriate age, including information on how they acquired HIV. In addition, knowledge on ART as a lifelong commitment, enabling them to enjoy a normal life, is crucial and requires repeated reminders and support. Hence, the diverse information about HIV derived from the community, schools and hospitals, influencing ALHIV's perception about HIV, is discussed in the subsequent section. Evidence from ALHIV's stories suggest that the initial knowledge about HIV has been mainly acquired at schools, nonetheless to comprehend

where ALHIV's perceptions and imaginations stem from, the sources of HIV-related information were further explored.

4.4.1 Community understanding of HIV

Because participants lived in constant fear of being discovered as HIV-positive and therefore facing discrimination, it was important to identify the community's knowledge about HIV and how PLHIV are regarded in the general public, from the viewpoint of ALHIV. According to the participants' experiences, due to inaccurate HIV information, people in the community still construct HIV as a dangerous "killer disease", linked to a premature death sentence, instigating the need to sideline the affected population. ALHIV were frequently subjected to people negatively debating topics around HIV, often guided by misinformation, such as HIV transmission through "normal" contact, HIV changing the physical appearance of PLHIV through severe weight loss or that women living with HIV would always deliver sick babies. These beliefs fuelled the community's fear of HIV and PLHIV, and consequently led to stigma and discrimination. Nevertheless, some ALHIV assumed that, with accurate information about HIV, the level of discrimination could be reduced. Interestingly, Daligo explained that he would not have a problem with his HIV status, but his major concern is dealing with HIV-related stigma, which needs to be addressed accordingly:

"To get out messages through the radio so that people should know that stigma is not good, they should not stigmatise people with HIV." (Daligo, male, 18)

Generally, ALHIV had the impression that the community, due to social stereotyping, exclude and categorise PLHIV apart from the HIV-negative population. However, also regarding the more formal source of information conveyed at schools, some ALHIV were of the opinion that outdated evidence would be spread, triggering an inappropriate perception of what it means to live with HIV.

4.4.2 Lessons about HIV at schools

Some participants considered the HIV education provided at school helpful, however, consistent with the messages noted within the communities, others evaluated the content of the HIV lessons inadequate due to schools' main focus on HIV prevention; only a few participants reported having learnt about ART as treatment for HIV. Nevertheless, participants also explained that at school, HIV, presented as "killer", was closely linked to inevitable death. Lydia remembered, that before she knew her HIV status, she first heard about HIV at school through learning the following educational song:

“AIDS is a killer, it has taken so many people, we are going to the graveyard. You have to take care, take care of yourself.” (Lydia, female, 13)

For her, this song was missing the information about “living positively with HIV”, therefore she did not recommend it for teaching:

“No, if I would be a teacher, I cannot tell the children about this song, because the song is somehow not complete. They just mention ‘Prevent, prevent HIV’, they don’t mention about how people can live positively with the medication.” (Lydia, female, 13)

Furthermore, Anne, who first learnt about HIV from her mother, found the ABC (**A**bstain, **B**e faithful, use a **C**ondom) approach delivered at school impractical for the Malawian context, as in male-dominant societies, men would often have multiple intimate relationships simultaneously and avert condom use. She described even leaving the classroom during HIV lessons to avoid feeling distressed:

“...because teachers don’t have basic knowledge about HIV. They have this information of HIV, which is wrong...the way the teacher was presenting the HIV topic in class caused more stress to me.” (Anne, female, 18)

Also a service provider shared an experience with an adolescent client concerning the emotional impact of HIV education at school:

“...she was crying the whole week, because at school they were saying ‘AIDS is a killer’ and her, she knows that she is HIV [positive]...” (Eveless, female, 32)

While in schools the educational focus is mainly set on HIV prevention, leaving pupils living with and being affected by HIV behind, the emphasis of the HIV education in hospitals is placed on “living positively with HIV”, which may contribute to tensions between HIV-positive and HIV-negative adolescents. Participants’ comparisons of the teachings at schools and hospitals have been discussed and are presented in the next section.

4.4.3 Information about HIV at hospitals

Not only does the information circulated within communities and schools have an impact on ALHIV’s perception of HIV, but also the HIV education in hospitals - often regarded as a safe environment, where HIV can be discussed overtly without the need for secrecy - has contributed to ALHIV’s understanding and perception of their condition. In contrast to the HIV

education attained at school, ALHIV evaluated the knowledge gained in hospitals as more detailed and open with a focus on ART adherence. Nevertheless, despite praising ART's effectiveness for their own benefit, the participants were not aware of the "Undetectable viral load equals untransmittable HIV infection" ("U=U") or "ART as prevention" concepts, increasing ART's advantage to intimate partners and their future children. The messages provided at hospitals were found more effective due to the inclusion of information regarding "living positively with HIV". This important distinction made them feel less threatened by HIV and more equal to HIV-negative peers:

"It's about adherence to medication, ...and another thing, that we should be equal to each and every one, the HIV-negative or the positive ones, there is no difference. People in our community should be at the same level." (Thalandira, female, 13)

While for Elmore the most important information received at the hospital included the understanding of HIV as chronic condition, not a death sentence, Jonathan preferred the open discussions about HIV at support groups to the HIV messages he received at school and the community:

"We talk about HIV as it is, we talk about sex as it is, we talk about condoms as it is. ... here at Teen Club [support group] it is more open, more direct. They don't hide anything."
(Jonathan, male, 15)

However, some participants reported uncertainty about these inconsistencies in HIV education, particularly regarding their life expectancy:

"At school they say HIV is a killer disease, but here at the clinic, they say HIV is not a killer disease." (Elmore, male, 15)

This confusion was also noted concerning ALHIV's beliefs about the duration of HIV in their body. While the majority of participants understood HIV as a chronic, lifelong condition, others were of the opinion that HIV will disappear one day. Ambiguity due to those discrepancies in information was reported also by service providers, creating doubtfulness in ALHIV about the truth. One service provider shared an experience of a client refusing to take ART due to the information received at school:

"But when she got the information from the teacher now, she thought 'Oh, that means that the guys at the clinic were telling lies.' Because the teacher now was saying 'Once you have

HIV, you are gone, you are dead.’, which was not the correct information and that’s how she decided to stop the medicines.” (Steve, male, 41)

Evidently, by placing emphasis on the aspect of living positively with HIV, the information provided at hospitals reduced ALHIV’s anxiety of HIV, ameliorating the information received from communities and schools. Therefore, service providers proposed aligning the HIV education offered at schools and hospitals to address this bottleneck, resulting in a population with an equal knowledge base. However, because participants mentioned the influence of hospital HIV books on their imagination of HIV, those books were, together with the participants, assessed.

4.4.4 HIV books used in hospitals

The following two images of HIV were taken from educational material ALHIV had access to:

Figure 4.1.

HIV in Book 1 used before disclosure



Figure 4.2.

HIV in Book 2 used during disclosure



Most participants were acquainted with Book 1, but some were also familiar with Book 2. Although several participants preferred HIV in Book 2 over that depicted in Book 1 due to a friendlier appearance, most participants evaluated the HIV representation in both books as dangerous, compromising their emotional wellbeing. Interestingly, few participants perceived the scary HIV images as beneficial to enforce ART adherence. Nevertheless, the use of pictorial education material within these books clearly inspired some participants in view of their choice of drawings. As such, two drawings were produced almost identical to the image of HIV in Book 2:



(Thalandira, female, 13)



(Woimba, male, 12)

Also considering that several imaginations of HIV were illustrated with sharp teeth, similar to HIV in Book 1, might confirm the huge effect of these images on ALHIV's perception and imagination of HIV. Still, most participants would prefer less dangerous, kinder HIV images in those books to alleviate fears and avoid distress and depression:

“If the teaching or the pictures are not friendly, the teaching is not in a friendly manner, that can give us depression, because we will always be thinking about the virus in a negative way. If the teaching is friendly, we will think about HIV in a positive way.” (Woimba, male, 12)

Furthermore, participants elaborated on the frightening images of HIV presented in teaching material, causing avoidance behaviour by HIV-negative people:

“That can make people think that those who have HIV and AIDS, they are people that cannot be friendly. That can promote stigma and discrimination.” (Anne, female, 18)

Importantly, the service providers also pointed out that a positive perception and imagination of HIV may enhance ALHIV's acceptance of themselves with this condition, mitigating fear and depression, which in turn, would improve their health. However, comprehending the concept of illness, specifically of a condition caused by an invisible pathogen, shifts with ALHIV's age and access to education. Exposing the participants to scientifically produced images of HIV under an electron microscope illuminated their perception regarding HIV in several directions.

4.4.5 HIV under the electron microscope

A transformation occurred during the research, when the following photos of HIV under an electron microscope were exhibited:

Figure 4.3.

Electron micrograph image showing HIV (in blue) on a CD4 cell from R. Dourmashkin / Wellcome Images via Cell Image Library (Australian Academy of Science, 2018)

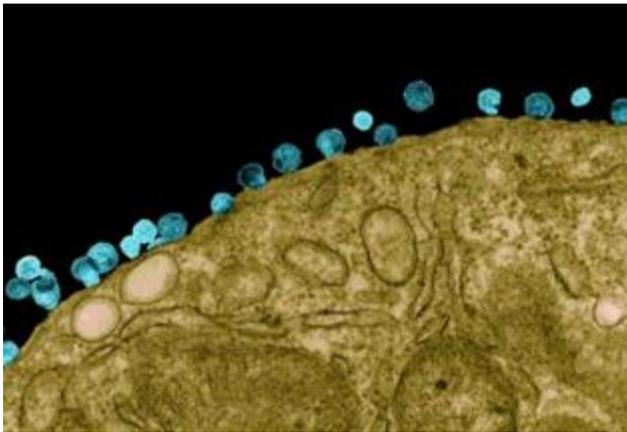


Figure 4.4.

A single HIV on a CD4 cell from Peter Arnold / NIAID/NIH (Human Diseases and Conditions, 2022)



For all participants it was their first time viewing HIV in this form, and they appreciated gaining this insight while recognising differences between HIV on the drawings, in the hospital books and the photo:

"I am feeling much better, because I know now how the real virus looks like."

(Thalandira, female, 13)

Although most participants expressed happiness about HIV's simple and friendly appearance, some participants attributed a negative feeling viewing HIV on the photo. They described it as appearing dangerous, resembling fire, interpreting the shadows on HIV as faces, and some perceived the photo with a single HIV-virus as less dangerous compared to that capturing multiple HIV-viruses. Due to the familiarity with humans, animals or insects, few participants evaluated the drawings made during the research as gentler. Nevertheless, those participants, considering HIV on the photo as friendlier, attributed this perception to the absence of body parts, such as faces with sharp teeth or toes with claws:

“In the past I thought that the virus looks dangerous and when I saw the real picture, I saw that the virus has no eyes, no legs, it is the same like cells in the body. I feel now better.”

(Anne, female, 18)

Also in comparison to the HIV image illustrated in the hospital HIV books, most participants preferred the appearance of HIV on the photo, judging it as more suitable for teaching purposes and suggested its inclusion in those books, generating a homogeneous perception of HIV. Furthermore, regarding the impact of knowing how HIV looks like under the electron microscope on their emotional wellbeing, most participants expressed that this understanding may reduce emotional distress and fear of HIV:

“It will be less stress or psychological problems, because of the way the virus looks like.”

(Thalandira, female, 13)

Some participants even advised including the image of HIV under the electron microscope in school books in order to eliminate misconceptions about HIV. In view of Malawi’s storytelling culture, participants also commented on the need of a suitable story, explaining HIV in a comprehensive way, when including these photographs. Because the use of war metaphors might be compelling for explaining HIV, it needs to be considered that stories about HIV and HIV illustrations may have detrimental effects on ALHIV’s emotional wellbeing and behaviour.

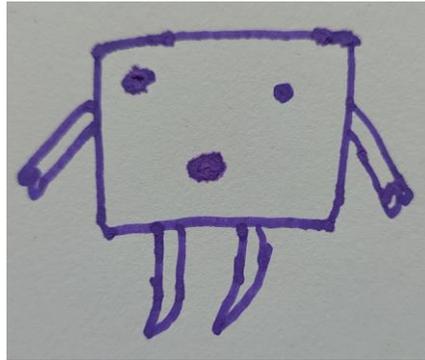
4.4.6 Emotional responses

The following section focuses on ALHIV’s emotions, which were induced by their HIV perceptions and formed by formal and informal HIV information. Presumably attributed to the secrecy and silence around HIV, as previously discussed, participants did not talk directly about their emotions. Most emotions were revealed during the FGDs when feelings towards the drawings and visual education material were discussed. Nevertheless, during the IDIs and FGDs, positive emotions such as happiness were reported in view of support, such as by support groups and the hope they have for a successful life. Also, ambiguous or neutral emotions were elucidated during the interpretation of participants’ drawings. Furthermore, sadness, anger and uncertainty were stated as negative emotions with fear most frequently mentioned in the context of fear to forget taking ART, fear of illness and death, fear of discrimination and stigma, fear of threatening HIV information, fear when they got to know they live with HIV and fear of letting others know their HIV status. Yet, ALHIV did not reveal directly the fear of the HIV-virus itself in their bodies, despite the often-scary creatures brought onto paper.

Nonetheless, most participants evaluated the emotional effect of the drawing activity as positive, indicating that they felt a form of relief during the drawing. Interestingly, sensations of HIV escaping from their body onto the paper were elucidated, demonstrating the therapeutic value of art. Additionally, their feelings towards the completed visual product was described as positive by most participants, however some observed negative feelings, described as “scary” when inspecting their drawing. In regard to ALHIV’s preferred HIV images, connected to the emotions they may provoke, the female participants aged 13-14 categorised the drawings during the FGD according to characteristics, such as “friendly versions of HIV” in form of a human being:



(Shanita, female, 14)



(Patuma, female, 14)



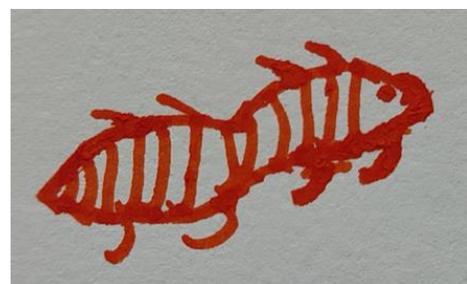
(Chisomo, female, 15)

“We cannot fear a human being, because we are human.” (Lydia, female, 13)

Also HIV portrayed as insects was not found threatening:



(Lydia, female 13)



(Mkango, male, 12)

Notably, a friendly HIV image was linked to better emotional wellbeing, facilitating the acceptance of the HIV status and promoting good ART adherence. On the other hand, the scary drawings of HIV were linked to dangerous animals, ghosts and monsters:



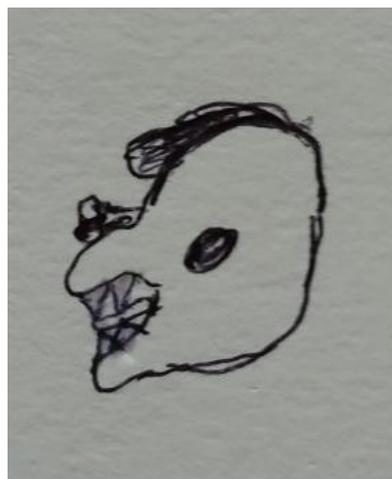
(Jonathan, male, 15)

“...look like a scorpion and we know a scorpion is dangerous.” (Shanita, female, 14)

Particularly the following drawings were recognised as frightening due to the sharp teeth, which could negatively impact mental health and ART adherence:



(Anne, female, 18)



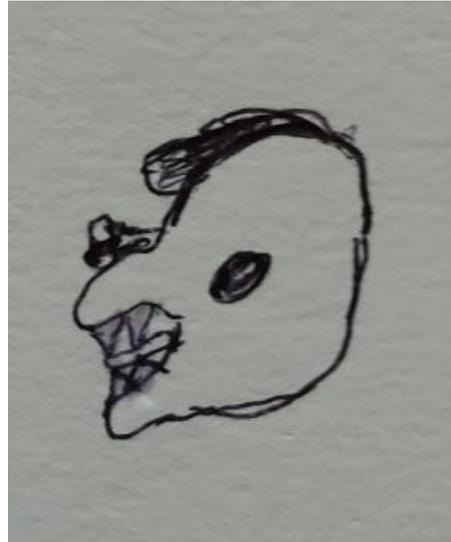
(Mishello, male, 10)

“This drawing can give stress to someone, who is taking ART, and it can make someone to kill herself, because of the way it looks.” (Lydia, female, 13)

Similarly, during the FGD with the four boys aged 10-14 years, the drawings were organised according to “friendly” and “scary” HIV images. They identified the following drawings as scary due to the scorpion’s scissors and the sharp teeth:



(Jonathan, male, 15)



(Mishello, male, 10)

These boys judged scary HIV imaginations to cause fear and depression:

"If you miss a dose one day, you will be thinking, because it's scary, ...you will die."

(Lion, male, 13)

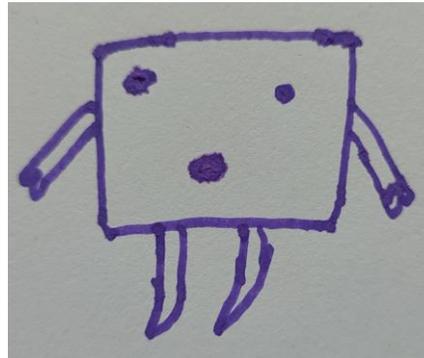
Conversely, the friendly drawings of HIV were found to have a positive impact on the emotional wellbeing:



(Lion, male, 13)

"...this one looks friendly."

(Lion, male, 13)



(Patuma, female, 14)

"It just looks like a small object."

(Mkango, male, 12)

Therefore, they suggested using friendly HIV images for teaching purposes to maintain or improve ALHIV's emotional wellbeing. Likewise, the girls aged 15-18 acknowledged during the FGD that HIV was portrayed scary on most drawings, which might cause fear and stress and therefore was considered as negatively impacting emotional wellbeing. During the FGD with

the boys aged 15-16, the same concerns regarding the scary HIV drawings were pointed out. They agreed that imagining HIV in a dangerous way may cause questions, fear and depression, while friendly perceptions may give peace of mind. The service providers equally believed that imagining HIV in a threatening way may negatively affect ALHIV, as by feeling “different”, they may isolate themselves from HIV-negative peers. Thus, for adopting a positive identity with HIV and alleviating the feeling of being different due to HIV, the importance of support groups and the potency of HIV education has been highlighted.

4.5 Conclusion

This chapter presented the identified themes central to how ALHIV imagine the HIV-virus and in what ways these images and the language used for HIV impact on their emotional wellbeing, perceptions and lived experiences. The participants’ narratives were augmented by their insightful drawings of the HIV-virus and explanations thereof. HIV was mainly portrayed with characteristics of human beings, insects and animals, including frightening features, such as sharp teeth or long nails to fight against ALHIV’s body. In exploring ALHIV’s imagination and perceptions of HIV, the language used for HIV was, due to its stigmatising nature, found to be surrounded by silence and secrecy. Additionally, the local term used for HIV “Kachilombo” was perceived with ambiguity; it might augment misperceptions, but, due to its double meaning, its use was also recognised as protection against HIV-related stigma and discrimination. Moreover, exemplified by the information received about HIV, ALHIV frequently used war metaphors when talking about HIV. Their understanding of HIV, resulting from formal and informal HIV education acquired in schools, hospitals and the community, exhibited discrepancies depending on whether the obtained information was aimed at audiences’ need for HIV prevention or “living positively with HIV”. Furthermore, the use of visual material depicting “HIV monster figures” in books to explain HIV and their impact on ALHIV’s visualisation of HIV in comparison to an image of HIV under the electron microscope has been discussed. Lastly, ALHIV’s emotional response towards HIV with regard to their perception and experiences was presented. The additional elucidation of the findings from the viewpoints of experienced service providers enriched the thematic understanding. The following discussion chapter will critically debate these findings in relation to the existing literature.

CHAPTER 5: DISCUSSION

5.1 Introduction

This chapter discusses the empirical findings of the qualitative study, which investigated how ALHIV's imaginations of HIV, and the language used for HIV impact on their emotional wellbeing, perceptions and lived experiences. The key findings of this study showed that ALHIV's imaginations of HIV were primarily shaped by formal and informal HIV education and the language used for HIV, including the local term for HIV, war metaphors and the silence and secrecy around HIV. The diverse HIV imaginations had an impact on their emotional wellbeing, suggesting that HIV education could adopt a more critical approach, which will be discussed later in this chapter. To enable emotional wellbeing, individuals living with HIV would benefit from a more holistic HIV education with verbal and pictorial HIV communication considering the learners' age, maturity, gender and background. Since the theoretical underpinning of this research has been introduced in the methodology chapter, the findings of this study are interpreted from a social cognitive perspective, providing a helpful structure for gaining insight into participants' learning, understanding and behaviour regarding HIV. Furthermore, the methodological contributions, particularly the benefits of using an arts-based approach and the contributions to knowledge and theory are discussed, followed by highlighting the study's strengths and limitations.

5.2 The language used for HIV

Language, as an important tool for communication and for conveying information (Park, 2016), has an impact on individuals' perceptions (Lupyan et al., 2020) and emotions (Lindquist, 2021). Terminologies used for certain conditions evidently impact on health-seeking behaviour and treatment adherence, but also on mental and physical health outcomes (Abubakar et al., 2013). Consequently, when communicating HIV-related information to adolescents, age-appropriate and sensitive language is needed for people to be able to understand and digest the concepts and meanings brought forward. This section discusses how the languages used for HIV shaped ALHIV's perception and imagination of HIV and the impact on their emotional wellbeing.

Silence and secrecy

The findings illustrate that adolescents' experiences of living with HIV were mainly formed corresponding to a language of silence and secrecy. Growing up with HIV as a highly stigmatised condition, the majority of participants mentioned the indispensable need for secrecy, often instructed by caregivers, unfolding in the form of keeping silent about their HIV

status and the hiding of ART, as the pill bottles could unveil their HIV status. Also caregivers in a qualitative study including 11-13 year old ALHIV in Uganda and Zimbabwe counteracted HIV-related stigma and discrimination by the reinforcement of reticence, creating a form of double life and subduing the children's autonomy (Bernays et al., 2015). Frequently even close family members were unaware of participants' HIV status, which made ART intake in their communal homes challenging and impeded family support. The drawback of employing silence and secrecy to control HIV-related stigma and discrimination was that it caused a perception of being different and frequently promoted poor ART adherence as discussed in the literature review chapter. Strategies to reduce HIV-related stigma and discrimination in Malawi may benefit from more open discussions about HIV and elucidating the "U=U" message, which entails that with an undetectable viral load the risk of HIV onward transmission can be eliminated. This could decrease the fear of PLHIV and with that, reduce the stigma attached to HIV (Eisinger et al., 2019).

Consistent with the findings of the literature review, the majority of participants experienced disclosure, predominantly facilitated by healthcare workers and not by their caregivers, as a single event, and not, in accordance with WHO (2011) recommendations. Disclosure as an incremental process, accompanied and judiciously explained by caregivers enhances ALHIV's understanding of HIV, as well as their emotional wellbeing, especially immediately after they get to know their HIV status (Woollett et al., 2017). Correspondingly, ALHIV perceived the support group as a safe environment, where, detached from their isolation, open conversations about HIV were encouraged and thus, provided a parallel platform to the usual life of silence and secrecy. There, HIV was understood as a manageable condition, which was in sharp contrast to HIV education gained in schools and communities, where HIV was portrayed as "killer disease".

The additional demand of strict HIV status concealment put a huge burden on the already vulnerable ALHIV. This further complicated ALHIV's desire of normalcy, especially regarding their experiences of sexual relationships and the expected disclosure behaviour to their intimate partners. Understandably, the learnt and sustained need for secrecy cannot be presumed to suddenly peel off once entering the maturity for intimacy. From a public health point of view the obligation of HIV disclosure to intimate partners places a huge responsibility on ALHIV. Hence, with growing maturity ALHIV need to learn strategies to meet those responsibilities while mediating potential consequences (Mackworth-Young et al., 2021). Since the root causes of the dilemma lay in HIV-related stigma and discrimination, efforts directed solely at the ALHIV population may not tackle these challenges and therefore require a wider approach, including caregivers, schools and communities. The silence around HIV created a

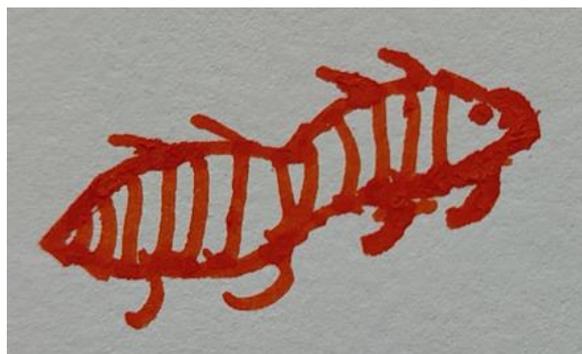
barrier impeding participants from making inquiries concerning HIV, and, despite considering it important to know how they acquired HIV, ALHIV felt uncomfortable asking questions. Similar observations were made in studies included in the literature review chapter, raising the importance of guidelines addressing negative emotions and providing strategies for strengthening their autonomy to facilitate HIV status disclosure, especially in intimate relationships (Gitahi et al., 2020).

Kachilombo

Attitudes towards HIV are shaped by the terms and images used for HIV, which generate distinctive, abstract realities, and reflect upon individuals' understanding and emotional response to it (Horne, 2004; Kamunyu & Bartoo, 2019). The SSA terms used for HIV are often figurative and metaphorical HIV representations. In Malawi, PLHIV are occasionally termed "wavulalira mkati", referring to "being damaged from the inside" (Muula, 2005), however, the more frequently local term used for HIV, "Kachilombo", can be translated as "small beast" (Moto, 2004), "small animal" (Conroy et al., 2013; Lwanda, 2002), "insect" (Kasahorow, 2022) or "virus" (Breitinger, 2011). This shows how African vernaculars convert medical or scientific terminologies for an invisible pathogen to symbolic, figurative language (Breitinger, 2011). Because communication about sex and HIV remains taboo in SSA, restricting related verbal expressions, the application of indirect terminologies aids in breaking the culture of silence surrounding these topics (Bastien et al., 2011). Nevertheless, the utilisation of these terminologies has been contested as they may contribute to misperceptions and stigma, and compromise HIV status disclosure (Anyango, 2012). They may also act as barriers to engaging with HIV testing and treatment (Uys et al., 2005). However, the participants' interpretations of the term "Kachilombo" varied from a dangerous, biting insect, which causes diseases, to a frightening and invisible invader, for which no cure was available. Understanding language as means for generating a perceptible product, the term "Kachilombo" stimulated some participants' choice of illustrating the HIV-virus as "small animal", "insect" or "beast":



(Ndazona, female, 16)



(Mkango, male, 12)



(Jonathan, male, 15)



(Anne, female, 18)

Aside from impacting ALHIV's visual imagination of HIV in their bodies, the consequences of using metaphorical terms for HIV were evident in relation to discrimination and stress, affecting their emotional wellbeing. Accordingly, a literature review by Vreeman et al. (2017) revealed mental health challenges among ALHIV globally (including Malawi), that were largely attributed to HIV-related stigma and discrimination.

As HIV is still a highly sensitive and stigma-related taboo topic in Malawi, the understanding of "Kachilombo" as a euphemism for HIV, shaped participants' HIV perceptions. For several participants, using the word "Kachilombo" in everyday talk was perceived as negative, discriminative and misleading due to the different meanings it carries. Moreover, during the interview conversations participants pointed out that "Kachilombo", defined as the singular form of HIV, neglects the presence of multiple HIV-viruses in the body, which could further lead to misperceptions. Just as language contributes to knowledge conception, it likewise serves emotive functions, which build different realities and perceptions (Mutonyi & Kendrick, 2010). This was confirmed by a study examining the terminologies used for HIV in the Democratic Republic of the Congo, where the factual labels of HIV, such as "insect" or "animal" created stigmatising behaviours through the differentiation of people living with or without the "insect" or "animal" in their bodies (Mupenda et al., 2014). Also in a study with Tanzanian children and ALHIV aged 9-19 years, the local term for HIV "vijidudu", translated to "small animals", was assumed to have impacted on participants' HIV perceptions and ART adherence behaviour (Mattes, 2014).

Comprehending HIV, for instance, as a stinging, blood sucking insect provoked fear in some of the participants in this study. Therefore, the local term "Kachilombo" should be used with

caution to avoid misunderstandings. Since terminologies play a crucial role when communicating HIV-related topics, the use of culturally appropriate and concurrently technically correct information is essential, especially in regions with high HIV prevalence (Lubinga & Jansen, 2011). With this understanding, the exclusion of local HIV vocabularies in the UNAIDS guidelines on HIV terminologies (UNAIDS, 2011) disregards their importance in guiding HIV knowledge and behaviour.

HIV war metaphors

For explaining complex medical constructs in lay language, since the 17th century war metaphors have been widely used in health communication concerning diabetes, cancer and different infectious diseases (Horne, 2004; Nie et al., 2016). Despite not visually represented on participants' drawings, HIV was verbally designated as the major actor of constant war scenes within their bodies. The participants frequently utilised war metaphors describing their sense-making of HIV with its physical effects and with ART as survival strategy. This language of war has been induced by teachers during HIV school lessons, where the emphasis of "HIV as a killer" leads to erroneous assumptions of living with HIV in the era of ART, enabling people to live a "normal" life with HIV. Similarly, the chosen language employed in hospital counselling sessions included fear-based messages to impart knowledge and reinforce expected ART adherence behaviours. Those kind of elaborations and the additional "HIV monsters" depicted in hospital HIV books profiled a picture of a destructive HIV-virus if ALHIV would be nonadherent to ART. The language and pictorial representations used for HIV affected how ALHIV perceived HIV and shaped their sense of an "HIV-positive" identity.

Interpreting diseases from a war perspective is considered controversial in literature (Horne, 2004). The advantage of employing war metaphors was found to increase patients' and healthcare workers' optimism regarding the process of recovery and to improve resource mobilisation for research (Casarett et al., 2010; Nie et al., 2016). Yet, while the focus of war terminologies mainly lies on the physical aspects of illness, they neglect the psychosocial and spiritual attributes of ill-health, making their use ethically disputable (Fuks, 2010). Adding to this dichotomy, considering the perceptions of patients being cured from cancer as "winners" and those with relapses or dying as "losers" in the "war against cancer" may leave the latter feeling disempowered and ashamed (Marron et al., 2020). Also recent COVID-19 education for children used the analogy of the virus as an invader which reproduces within the body (Jenner et al., 2020; Tapia et al., 2020). The emotional consequences through the use of war terminologies include negative feelings, such as fear, guilt, shame and demotivation (Hauser & Schwarz, 2020; Hendricks et al., 2018). In line with this, the UNAIDS guidelines on HIV terminologies (UNAIDS, 2011) discourage the use of war terminologies for HIV communication

to avoid the inference from a “war against HIV” to a “war against PLHIV”. For avoiding harm when communicating HIV-related topics, alternatively to the war terminologies currently used, a simple, honest and culturally appropriate language may promote the mutuality, equality and the same time the comprehension of HIV as presently chronic, manageable condition (LeBlanc et al., 2019; Reisfield & Wilson, 2004). In addition to the verbal HIV education, pictorial information to help explain HIV, was used in the hospital setting. The usefulness and impact of these pictorial HIV representations will be discussed in the subsequent section.

5.3 Pictorial HIV representations

Pictorial or visual illness representations of pathogens include drawings, pictures and photographs (Manches & Ainsworth, 2022), which, according to the CDC (2022), are useful for explaining complicated health information, especially in populations with reduced literacy skills. An integrative review, including adults, found that visual education material notably enhanced health literacy (Park & Zuniga, 2016). However, for effective visual communication, decisions on the choices of pictorial images need to consider the understandability and interpretation of the material, as well as the ethical and emotional appropriateness (CDC, 2022). Health education comics have been declared as a non-threatening tool (McAllister, 1992), being effective for awareness raising, but also for enhanced understanding and coping with a condition (McNicol, 2014). Conversely, the utilisation of scary HIV representations, such as monsters to explain HIV, may create misconceptions (Mutonyi & Kendrick, 2011; Wong et al., 2006). Misinterpretations of pictorial education material have been established by a study involving South African adults, who could not comprehend the abstract, symbolic meaning of pictorial metaphors, such as the “HIV monster” (Carstens et al., 2006). Additionally, a systematic review found threatening graphic warnings on cigarette packages to be ineffective for smoking cessation due to smokers’ reactions and evaluated the use of positive messages as more successful for behaviour change (Pang et al., 2021).

Nevertheless, several participants noted that their visual HIV perception was guided by hospital HIV books, which were presented in the form of comics and used to explain HIV. The HIV representations in these books were perceived as dangerous and compromising their emotional wellbeing. The majority of participants mentioned that a friendlier HIV image in educational books might alleviate fears and depression and thus, enhance self-acceptance, which in turn could improve their emotional wellbeing. They also noted that those HIV representations could cause stigma and discrimination when seen and be misinterpreted by people not living with HIV. As the consequences of employing threatening verbal language in HIV education was previously discussed, also the social and emotional impact of using non-

verbal, pictorial HIV representations needs to be evaluated when developing or using such health communication material (Houts et al., 2006).

In a hospital HIV book for adult PLHIV, similar HIV representations (Figure 5.1.) are used to explain HIV:

Figure 5.1.

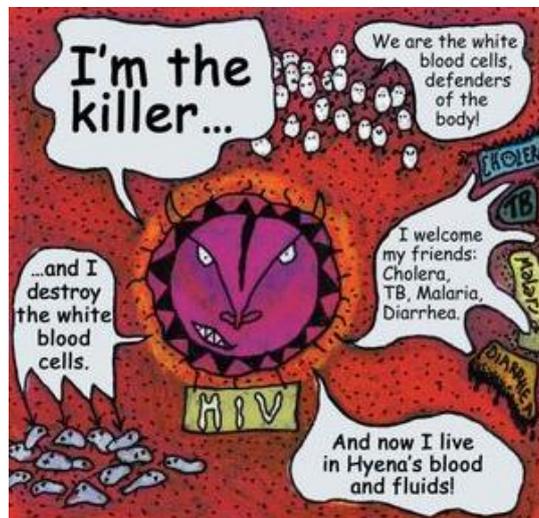
HIV (Tingathe, 2015)



Furthermore, an educational book for students in a Malawian community aimed at increasing HIV-related knowledge for HIV prevention, equally portrait HIV as a “killer”:

Figure 5.2.

HIV (Ringbom & Wiklund, 2006)

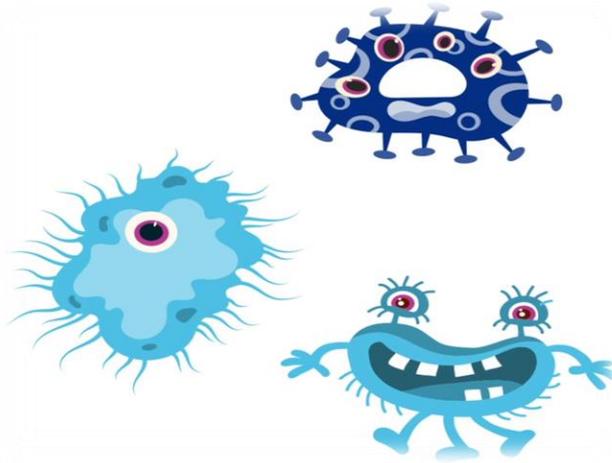


This book was found to increase HIV-related knowledge, however, the impact this book had on emotional wellbeing or HIV-related stigma and discrimination has not been explored

(HEEED-Malawi, 2008). Correspondingly, a similar health communication strategy has been followed regarding the Coronavirus, mediated as an enemy at war with humankind. Again, a “monster” called Coronavirus (Figure 5.3.) has been portrayed with a face and teeth that might aggravate negative emotions, reaching directions beyond knowledge acquisition (Barreneche, 2020).

Figure 5.3.

COVID-19 (Boston Children’s Hospital, 2022)



According to Manches and Ainsworth (2022), children have the cognitive capacity to understand the biology of invisible viruses, provided their representation is pertinent.

Although it was not the aim of this study to rectify participants’ HIV imaginations, images of HIV under the electron microscope, as alternatives to the HIV representations in the hospital HIV books, were presented and discussed. Since the literature review findings showed ALHIV having insufficient detailed information on the nature of HIV, exposing the participants to scientifically produced HIV images illuminated their HIV perceptions in several ways. All adolescent participants valued the exposure to these images and most revealed positive emotions towards HIV’s simple and friendly appearance on these pictures, especially due to the absence of body parts. Comparable remarks were made by Malawian ALHIV, who participated in an art therapy workshop in 2016 (Picturing Health, 2018). Furthermore, ALHIV mentioned that, in comparison to the aggressive HIV representations in hospital HIV books, the scientific HIV images under the electron microscope could demystify HIV and thus, reduce emotional distress and fear. Suggestions of integrating those scientific HIV images in educational material were raised. In spite of the advantages of blending verbal and visual properties into HIV education material, these sources require quality control and pretesting in view of their effectiveness regarding the context and the target age groups.

5.4 HIV imaginations

Inspired by the term “Kachilombo” and hospital HIV books, most ALHIV imagined the appearance of HIV as a living creature with human, animal or insect features, a gender identity, functional senses and nutritional needs. In Appendices 35 and 36 the complete set of drawings produced by all adolescent participants are illustrated. The meaning they attached to HIV’s personification was that of a dangerous and harmful creature in their bodies, especially when ART was not taken, because then HIV was believed to be awake, moving and performing a fight within their bodies. The personification of invisible pathogens invading a human body illuminated their existence as physical and at the same time as a psychological threat (Connelly & Macleod, 2003). Guided by fear, HIV was ascribed a mean character with threatening attitudes. This negative image of HIV had adverse implications on ALHIV’s emotional wellbeing.

Nevertheless, several participants considered HIV to be nonviolent as long as they took their ART as prescribed, since they believed ART would force HIV into a dormant state. Those perceptions indicate the ways ALHIV tried to make sense of HIV, including the comprehension of HIV’s intentions and functions within their bodies. Consequently, the extremely different realities in how ALHIV exhibited HIV as visual products on paper ranged from HIV as a scorpion to HIV as a girl in a blue dress:



(Jonathan, male, 15)



(Shanita, female, 14)

These diverse realities stemmed from ALHIV’s social interactions with their environment, comprising formal and informal learning about HIV, as well as the figurative and metaphorical language used for HIV, previously discussed.

The implications of ALHIV's perception of HIV are far reaching. For instance, ALHIV regarded HIV as unsolicited harmful intruder, with whom they not have a direct relationship. Similarly, children with cancer in India described cancer as invading their bodies (Sadruddin & Hameed-ur-Rehman, 2013). Also, studies with adult cancer patients in Canada (Stephens & Thorne, 2022) and Australia (Rashidi et al., 2021) confirmed comparable perceptions of different types of cancer as intruders, taking over their identity. In order to dissociate from the view of cancer as an "external invader", Lucas (2022) suggested placing the emphasis on strategies to reduce the multiplication of cancerous cells. With regard to HIV, a similar approach could be applied in view of ART for controlling the multiplication of HIV ("U=U"). These findings led to the assumption that ALHIV used HIV's personification to understand and express its appearance, functions and meanings. Despite the fact that illness personifications may be influenced by culture, gender and age, similar illness personifications were used by Nicaraguan PLHIV when referring to a "sleeping HIV-virus" through ART as a controlling agent of HIV (Vasquez, 2015). Moreover, in a study exploring illness meanings among female PLHIV aged 18-24 in the US, HIV has been portrayed as a "gremlin", implying the perceived "physical, social, and emotional threats posed by HIV" (Scott, 2009).

Similar imaginations were found in drawings produced by Dutch adults, who depicted their tumours in the form of monsters, demonstrating their illness perceptions (Van Leeuwen et al., 2015). Previous work on illness perceptions found 6-18 year old Mauritians with chronic conditions using illness personifications for explaining the conditions' purpose and activity in their bodies (Kane & Fearon, 2018), which was also observed in drawings of pain personifications among 5-18 year old Canadians (Unruh et al., 1983). Correspondingly, Spanish pupils aged 9-10 years demonstrated their understanding of death as anthropomorphised personification, such as "death as killer" in their drawings (Vázquez-Sánchez et al., 2019), which was also established in a study with Taiwanese children and adolescents aged 8-16 years (Yang & Chen, 2002). These findings call into question the sources of those perceptions and in how far the negative, threatening personifications of ill-health or death serve the purpose of imparting knowledge ethically, considering the implications for individuals' emotional wellbeing.

Surprisingly, the participants have not described their visual HIV imagination as a spiritual being, however this was anticipated, considering their cultural beliefs and the findings from research in Ghana, illuminating HIV as spiritual attack (Okyerefo & Fiaveh, 2017) or in Zimbabwe, where HIV was understood to be a spirit within the human body (Shoko & Chiwara, 2015). A possible explanation therefore could be that either the participants did not perceive HIV from this perspective, that the hospital environment, where the data were collected, was

not felt appropriate for verbalising these perspectives, or alternatively, they felt uncomfortable sharing this information with the researcher, who came from a foreign country with different belief systems.

With respect to the research question, investigating the ways that imaginations impact on participants' emotional wellbeing, the findings highlighted conflicting opinions. Some participants perceived a friendly imagination of HIV linked to better emotional wellbeing and facilitating good ART adherence. Therefore, several participants proposed the inclusion of friendly pictorial HIV representations in teaching material. While this could ameliorate the misinformation received, extending these findings to school curricula could close the knowledge gap between ALHIV and their HIV-negative peers and thus, provide an equal knowledge base, with the potential of reducing HIV-related stigma and discrimination. Considering emotions as catalysts for health behaviour, pictorial HIV representations, evoking emotions among ALHIV need to be selected cautiously. Other participants, in contrast, stressed the importance of imagining HIV as a frightening creature, which might positively impact ART adherence due to fear, instigating pressure to adhere to ART and thus, find peace in forcing HIV into a nonviolent state. However, for a few participants, ART alone was unable to change the general perception of powerlessness against HIV in their bodies. With this in mind, and the prior discussion regarding advantages and disadvantages of using fear-based HIV communication, it might be argued that a one size fits all educational approach may not work for all ALHIV. Therefore, in order to improve ALHIV's understanding of HIV, accurate and uniform knowledge about HIV may reduce their misperceptions and enhance their emotional wellbeing.

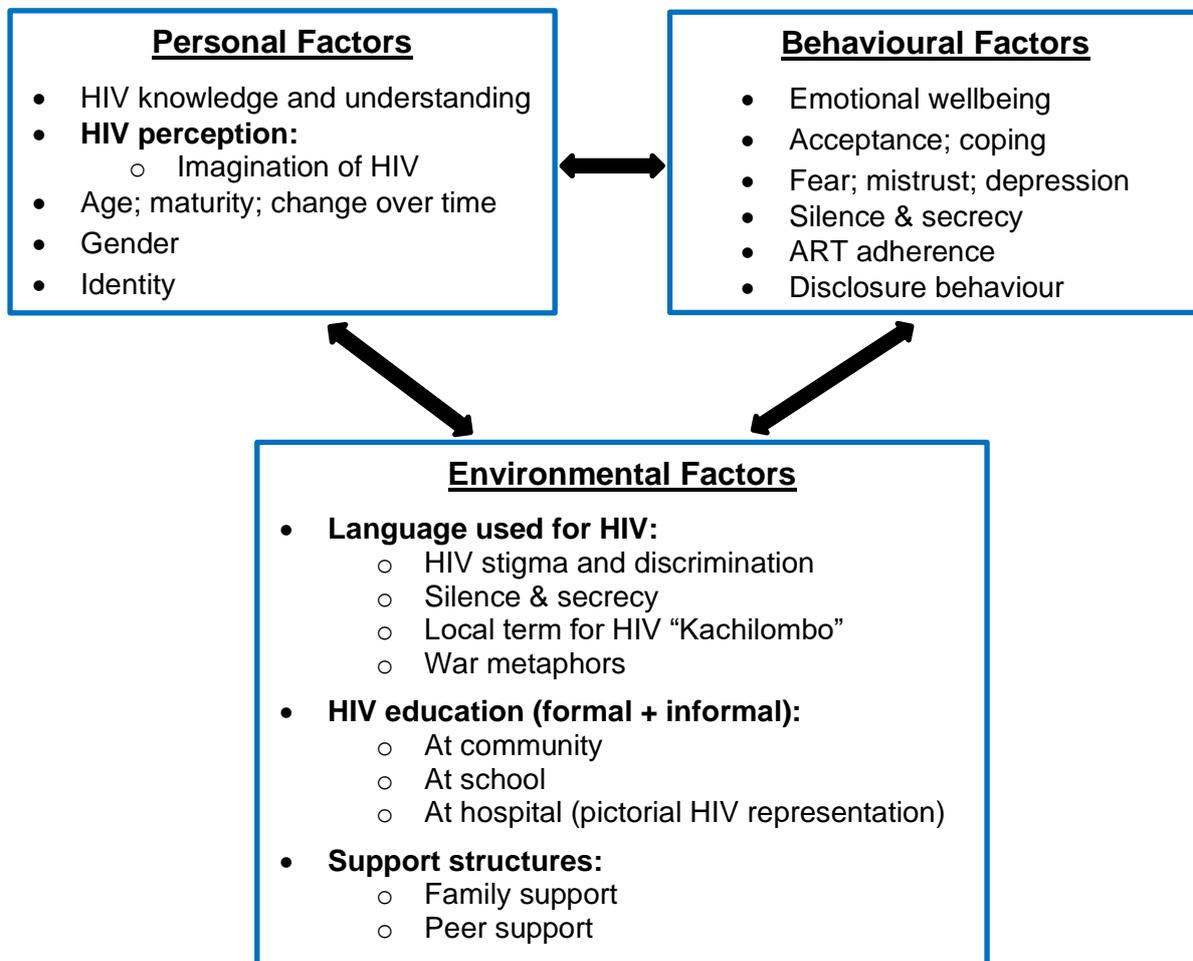
5.5 Interdependent domains within the SCT

As highlighted in the methodology chapter, the SCT was evaluated as a useful and dynamic model for understanding and explaining the empirical findings of this study, especially with regard to the three domains (environmental, personal, behavioural), which stand in reciprocal relationship to each other. These synergies helped to elucidate the barriers and facilitators impacting on ALHIV's emotional wellbeing. While the influential extent of each domain remains uncertain, environmental factors were identified as important influencing factors, highlighting the importance of ALHIV's social environment for learning about HIV and its capacity to internalise positive or negative emotional wellbeing, which was dependant upon the experiences made within the social environment and the perceptions framed through social interactions and cognitive processes. This had not only an impact on their emotional wellbeing,

but likewise on their attitudes and behaviour, such as ART adherence. Figure 5.4. visualises the three domains and their interdependence.

Figure 5.4.

Bandura's Social Cognitive Theory applied to HIV perceptions and emotional wellbeing (adapted from Bandura, 1993)



The SCT was helpful for understanding the mutual influences the different domains have on each other. In this study the behavioural factors comprised ALHIV’s emotional wellbeing, supported by the acceptance of their HIV status, feelings of trust, fear and depression, the need for secrecy, ART adherence and disclosure behaviour. Those factors were linked to the personal and environmental factors. The personal factors, influencing ALHIV’s behavioural factors included - besides their identity, maturity/age and gender - their perceptions, knowledge and understanding of HIV, which were shaped by environmental factors, such as the language used for HIV, formal and informal HIV education, as well as the availability of support structures. For instance, the participants mainly perceived the language used for HIV

(environmental factor) as intimidating due to the high levels of HIV-related stigma and discrimination, which in turn necessitated silence and secrecy (behavioural factor). This silence was often imposed by their caregivers (environmental factor), impacting on ALHIV's emotional wellbeing, their HIV knowledge, perceptions (personal factors) and disclosure behaviour (behavioural factor). Also the local term employed for HIV "Kachilombo" (environmental factor) caused misperceptions (personal factor) due to its equivocation, since this expression is used in parallel for insects in Malawi, and thus, it clearly guided ALHIV's imagination of HIV, as evidenced on some of their visual products. Furthermore, war metaphors (environmental factor) employed to explain HIV, contributed to ALHIV's fear and perception of living with a humanised enemy in their body (behavioural factor). Conversely, the contradicting HIV education (environmental factor) with HIV portrayed as a "killer" at school and the community on the one hand, and as a manageable condition in the hospital on the other hand, caused confusion and mistrust (behavioural factor).

The results suggest that ALHIV conceptualise their individual meaning regarding HIV. Their HIV perceptions (personal factor) facilitated a potential for negative emotional responses (behavioural factor). However, as ALHIV's emotional responses (behavioural factor) likewise influenced cognitions and perceptions (personal factors), a positive emotional wellbeing could result in more positive attitudes towards HIV and themselves living with HIV. For instance, HIV perceived as a dangerous intruder caused fear, which in turn led to negative emotions, and silence and secrecy. A friendly HIV imagination in contrast, was perceived as reducing fears and with that, enabled a more positive emotional wellbeing, facilitated adolescents' coping with their condition and better ART adherence.

The interdependence between these three domains can be positive or negative, and contingent upon that, they directly or indirectly shaped ALHIV's perceptions and emotional wellbeing. Yet, ALHIV are active mediators, who affect and are affected by their social environment and thus, should be given more agency when planning and implementing HIV interventions. Understanding HIV as a chronic and manageable condition, ALHIV could benefit if the perceptions around HIV were oriented towards health, rather than towards disease as suggested by the salutogenesis model, which focuses on health creation and emotional wellbeing through available resources (Antonovsky, 1996). As such, interventions could utilise and build on the environmental facilitators that positively impact ALHIV's emotional wellbeing, including continuous access to support structures and appropriate HIV education.

The detrimental effects of negative emotional wellbeing on ART adherence among ALHIV have been widely acknowledged (Byansi et al., 2021; Hudelson & Cluver, 2015; Nguyen et al., 2022;

Okawa et al., 2018). Accordingly, gaining an understanding of the elements recognised as positive facilitators for ALHIV's emotional wellbeing (Table 5.1.) can guide the developments of age appropriate and culturally sensitive social, emotional and informational support interventions.

However, as stated in the methodology chapter, the SCT accounts for age under the domain personal factors, but it fails to capture individuals' levels of maturity, which is of importance regarding the immense changes and development which occur during adolescence. Therefore, this study contributes to theory development with the addition of maturity into the personal domain since this was important for the context of this study. Additionally, dividing adolescence for this study into two age groups with younger adolescents aged 10-14 years and older adolescents aged 15-19 years, has enabled a distinction in view of participants' cognitive abilities, autonomy and decision-making processes. However, development and maturity is not identical for all adolescents with huge divergences in cognitive, psychosocial and physical growth (Icenogle et al., 2019). Considering that age and maturity are not linear during adolescence, placing a focus only on age, as endorsed within the SCT, may lead to false assumptions. The comprehension of illness concepts, specifically of a condition caused by an invisible pathogen, shifts with ALHIV's level of maturity and access to education. For instance, HIV status disclosure at a young age gives the ALHIV more time to build resilience and come to terms with their HIV status versus ALHIV, who learn about their diagnosis at an older age, where they must manage a chronic condition with daily ART intake and frequent hospital visits alongside other rapid changes occurring in their lives. Hence, instead of judging ALHIV's needs, abilities and understanding of HIV by their age, approaches considering the individual level of maturity are deemed to be more appropriate. Moreover, the SCT does not account for changes occurring over time, but particularly in adolescence, where numerous biological and hormonal changes are taking place in a relatively short time, the domain of time plays a role regarding ALHIV's emotional wellbeing, perceptions and lived experiences. For allowing a multidimensional and holistic understanding of the phenomenon, the time factor is important to be taken into account.

Table 5.1.*Barriers and facilitators impacting on ALHIV's emotional wellbeing*

SCT domain	Barriers	Facilitators
Environmental factors	Stigma and discrimination	Reduced stigma due to HIV knowledge
	Silence and secrecy	Open discussions about HIV
	Local term "Kachilombo"	Use of local term with caution to avoid misunderstanding
	Conflicting HIV information: HIV education at school (HIV as killer) Informal HIV education in the community (misperceptions about HIV) HIV education in hospitals (Living positively with HIV)	Uniform HIV education to achieve an equal knowledge base among all
	Pictorial HIV representations used in education	Pictorial HIV representations to be friendly and tested for the Malawian context before use
	Lack of autonomy in disclosure decisions	Strengthened disclosure capacity Stable support structures: Caregiver support Support group
Personal factors	Inaccurate knowledge about HIV Misperceptions about HIV	Accurate knowledge about HIV
	Age; maturity; change over time	Age; maturity; change over time
Behavioural factors	Depression, fear, mistrust, feeling different to peers	Acceptance of HIV status, coping
	Silence and secrecy: No disclosure (to intimate partners)	Disclosure (to intimate partners)
	ART non-adherence	ART adherence

To attain a responsible disclosure behaviour, ALHIV need to gain self-confidence, which might be strengthened by accurate knowledge about HIV and positive emotional wellbeing. Hence, for ALHIV entering sexual maturity, a programme familiarising them with the

“Undetectable=Untransmittable” concept may enhance their HIV perception and provide hope regarding their future family planning. However, this knowledge is not crucial solely for the ALHIV population, and could therefore be disseminated on a nation-wide scale, for instance in form of a stigma reduction strategy to change ALHIV’s environmental barriers to gain emotional wellbeing and enhance their confidence and autonomy for disclosing their HIV status to others.

5.6 Methodological contributions

The arts-based approach has enabled young people to express themselves. The created images are powerful in their own right, but they also acted as a vehicle enabling insightful and intimate conversations about participants’ experiences. In the literature review chapter the findings suggest that the most frequently used qualitative data collection methods were single IDIs, followed by single IDIs with subsequent FGDs or solely FGDs. Regarding the inclusion of participants, it was largely only ALHIV who were involved. None of these studies used the approach employed in this present study, comprising semi-structured IDIs, repeat IDIs, FGDs and an arts-based data collection method. This triangulation of data collection methods facilitated a deeper insight into the phenomena explored. Consequently, including a follow-up IDI generated richer narratives due to the established trust, which allowed the participants to respond more open in the second IDI. Moreover, the follow-up IDI allowed participants to validate the themes revealed in the first IDI, which participants further interpreted during the FGDs.

The participants found it challenging to verbally describe their HIV imaginations. Therefore, the methodology was additionally strengthened by the inclusion of the drawing activity, which provided a time of creative silence and concentration, allowing the participants to go deeper into their perception and imagination of HIV and convey it in a nonverbal, visual way (Sadruddin & Hameed-ur-Rehman, 2013; Welsh & Instone, 2000). The drawings speak for themselves, but the subsequent discussion of ALHIVs’ visual product brought deeper, richer nuances of their perceptions, which would have been much less impactful without the drawings (Ångström-Brännström & Norberg, 2014; D’Amico et al., 2016). This was noticeable as the participants had difficulties describing their HIV imaginations prior to the drawing activity, but through making their drawings, ALHIV were able to provide detailed explanations regarding their HIV imaginations. Nevertheless, the process of drawing was more important than the final visual product. In addition, the 2-4 weeks period to the follow-up IDI provided time for the participants to reflect on the conversation and their visual product, which was then again inspected and discussed. The therapeutic aspect of drawing contributed to a relaxed atmosphere, conducive

to collect in-depth data (Theron et al., 2011). Reviewing all visual products during the FGDs further enriched the participants' understanding, since they could realise similarities and differences in the diverse HIV imaginations. Also for the service providers these visual products were astonishing eye openers since they had not expected ALHIV holding such HIV imaginations. Additionally, reviewing and contrasting pictorial HIV representations used in hospital HIV books and scientific images of HIV under the electron microscope as alternative illumination of HIV, provided a wider horizon and exposed ALHIV's preferences of visual HIV education material.

Engaging translators with the same gender to the participants and the same two translators, who were already known by the adolescent participants, throughout the four months of data collection, ensured consistency of people involved in the research and thus, participants could feel comfortable and did not have to gain trust to different individuals. This arrangement could have forfeited the language quality for data transcription, however, it was strategically beneficial and ethically appropriate in case participants were to feel distressed during the conversations. Also, dividing the participants according to gender and age for the FGDs allowed them to relax and talk more freely about the sensitive topics concerning HIV. Several participants were grateful for the possibility of being able to talk about HIV in this safe space. Scheduling the FGD with the service providers as a final data collection point provided another layer of interpretation, engaging experts in this field reflecting on current practices and possible improvements in HIV education in terms of language used, but also in the way pictorial HIV representations in hospital HIV books are incorporated and further employed for explaining HIV.

5.7 Contributions to knowledge and theory

Adolescents living with HIV in Malawi face numerous challenges, including HIV-related stigma and discrimination, as well as lacking crucial information on HIV, which significantly impacts on their physical and emotional wellbeing. Their HIV perceptions have been explored by several studies in order to understand behaviour and mental health outcomes. Research on the effects of local terms used for HIV was scarce and ALHIV's perceptions regarding people's visual imagination of the HIV-virus and the pictorial HIV representations used in health education were an identified gap in the existing literature. Hence, this study was built on the current knowledge base through discernments, that could aid in guiding the development of culturally and age/maturity appropriate educational interventions to improve ALHIV's perception, emotional wellbeing and understanding of the condition, which in turn may have

an impact on the control of HIV and thus, on the development of Malawi. Consequently, this study has given a voice to the vulnerable population of ALHIV in Malawi, who usually feel required to keep silent about HIV and thus, live their lives shrouded in secrecy. Gaining an in-depth understanding of their realities of living with HIV, which were expressed by verbal and visual accounts, clearly provided a different perspective regarding ALHIV's perceptions of HIV.

Their descriptions, perceptions and representations of HIV were a result of the language used for HIV in Malawi, the exposure to conflicting HIV information and pictorial HIV representations in hospital HIV books, which further influenced ALHIV's emotional wellbeing. Regarding the language used for HIV, due to stigma and discrimination, the silence and secrecy around HIV imparted shame and fear of openly requesting HIV information, and even worse, rendered ALHIV unwilling to disclose their HIV status, which contributes to the continuation of HIV onward transmission. Furthermore, the figurative and metaphorical term used for HIV in Malawi, "Kachilombo", provoked confusion due to its equivocation as it is also used to describe insects. This created misperceptions regarding HIV as personification and anthropomorphisation in ALHIVs' bodies. Given the importance of terminologies in health communication, the use of culturally appropriate and concurrently technically correct information is essential. The utilisation of war metaphors when communicating information about HIV, further amplified ALHIV's misconceptions and negative emotional wellbeing.

In view of HIV education, ALHIV were exposed to conflicting information, including HIV as "killer" at schools and within their community, and HIV as a controllable condition at the hospital. Obtaining those contradictory messages regarding HIV introduced confusion and uncertainty about their verisimilitude. However, threatening pictorial HIV representations in hospital HIV books shaped their HIV perceptions and negatively impacted upon their emotional wellbeing. Notably, ALHIV perceived scientific images of HIV under the electron microscope less distressing, and therefore suggestions of integrating those HIV images into educational material were made. Considering that ALHIV's perceptions of HIV and their emotional wellbeing were strongly impacted by the language used for HIV, the conflicting HIV information and the effects of pictorial HIV representations, HIV communication and education strategies may need to be reviewed and evaluated in order to promote emotional wellbeing and thus, healthier behaviour, including ART adherence. Since education can transform HIV perceptions and facilitate social change, a more holistic and sensitive educational approach - employing positive reinforcement strategies - might be useful not only for populations living with HIV, but equally for those responsible for HIV-related stigma and discrimination.

This study contributes to the comprehension of how the SCT domains, relating to the HIV perceptions and experiences among ALHIV in Malawi, may influence health education, specifically in view of their understanding of HIV and emotional wellbeing. This lens has added insight into the relevance of the different SCT domains concerning the formation of knowledge and perception, and their interplay when investigating resulting consequences, such as emotional wellbeing and behaviour. However, to capture the different levels of maturity and cognitive, as well as developmental changes occurring in adolescence, a possible adaptation of this model with the consideration of individuals' maturity in addition to their age - as outlined in the previous section - might help mitigating the oversight of this important consideration. With this suggested theory adaptation, the study can provide novel contributions considering that attending to the individuals' maturity level and the integrated concept of time in HIV education may provide a more effective and holistic HIV care approach.

5.8 Strengths and limitations of the research

One strength of the study was, aside from presenting evidence to inform practice and future research, that a vulnerable population was given a voice. Moreover, the phenomenological approach provided rich insights into the perceptions of both genders, including eight male and eight female ALHIV, which may have reduced gender bias. The methodological strengths of this research, as outlined in the previous section, included that the drawings facilitated ALHIV's expression in nonverbal form, which then enhanced the discussions regarding their HIV perceptions. Additionally, the triangulation of qualitative methods enhanced the rapport building with the adolescents, permitted member checking, but also, discussing their experiences and perceptions repeatedly, may have impacted upon their lived experience regarding the usual silence around HIV. The facilitation of same-gender FGDs with the ALHIV may have reduced gender dynamics and maintained their level of comfort. Involving familiar translators, who were known by the participants, with the same gender as the participants and conducting the IDIs and FGDs with the adolescents throughout in the local language Chichewa, may have had positive effects on the data quality. The additional views and perceptions shared by experienced service providers offered further validation and enhanced the understanding of the phenomena.

Nonetheless, this research is limited in numerous ways. The generalisability of the findings, although not being the aim of qualitative research (Ritchie et al., 2014), is limited due to several reasons. Firstly, the findings reflect the perceptions of ALHIV enrolled in HIV peer support groups, benefiting from important HIV education and psychosocial support and thus, could differ from ALHIV who are not able to access such care and services. Secondly, because the

included participants (per self-report) acquired HIV perinatally, the findings cannot be extrapolated to adolescents not living with HIV or adolescents, who acquired HIV through other routes, as their experiences may vary. Furthermore, recall bias and social desirability might have impacted the responses, since the participants' accounts could have reflected on what they thought interviewers expected them to answer. In addition, due to the engagement of interpreters, euphemisms or culture-specific expressions may have lost their exact meaning during translations from Chichewa to English (Mphande, 2020). Also, transcribing the data solely in English, without the review of a language expert, may have introduced translation bias. A further limitation of the study includes the researcher's direct involvement and influence, which may have caused observer bias. However, this was addressed with the continuous application of reflexivity (Bryant, 2009).

5.9 Conclusion

This chapter critically evaluated the findings of the study in the context of existing literature and Bandura's SCT. Additionally, the methodological contributions, contributions to knowledge and theory, and the strengths, as well as limitations of the research were discussed. The findings demonstrate that the descriptions, perceptions and representations of HIV by Malawian ALHIV emerged from the language used for HIV, the exposure to conflicting HIV information and pictorial HIV representations in hospital HIV books, which often negatively impacted ALHIV's emotional wellbeing. With the aim of impeding factors hindering ALHIV's emotional wellbeing, strategies need to acknowledge and build on the facilitators enabling emotional wellbeing. Therefore, reflecting on and eliminating the present tensions in HIV communication and education could promote ALHIV's emotional wellbeing and improve their adherence to ART.

The following and final concluding chapter of this thesis will summarise the findings, highlighting the reflections on the research project, and present recommendations for practice and future research.

CHAPTER 6: CONCLUSIONS

6.1 Introduction

This qualitative study has given voice to an often neglected population. It revealed that ALHIV's imaginations of HIV were that of personified, harmful creatures in their bodies. Those perceptions were primarily shaped by HIV education and the language used for HIV, including the local term for HIV, war metaphors and the silence and stigma around HIV. The distinct HIV imaginations had an impact on their emotional wellbeing, suggesting that HIV education could advance to a more critical and holistic approach including verbal and pictorial explanations considering the individual's age, maturity, gender and background. In this last chapter recommendations for practice and future research will be suggested, followed by reflections on the research project.

6.2 Recommendations

Based on the study findings, which revealed some areas requiring improvement in the care of ALHIV in Malawi, a number of recommendations for practice and future research are discussed in this section.

6.2.1 Recommendations for practice

Regarding the HIV education in hospitals, a more holistic approach, considering the appropriateness of pictorial elements and the language used may enhance ALHIV's understanding and perceptions of HIV and thus, positively impact on their emotional wellbeing and adherence to ART. Therefore, it is important to involve ALHIV in the evaluation of current learning material, and equally during the planning and development of educational sources, for incorporating ALHIV's preferences and firsthand experiences (Wigle et al., 2020). However, this educational material needs to be pretested for its use with different audiences. Also, conveying accurate and appropriate HIV communication, including scientific images of HIV, to the wider educational context, such as in schools or HIV campaigns with up-to-date knowledge concerning "Undetectable=Untransmittable" with its medical and psychosocial consequences, could raise awareness and reduce HIV-related stigma and discrimination by portraying HIV as a manageable, chronic condition divergent from the depiction of HIV as terminal illness. Exposure to this information could reduce fear in the ALHIV population, but equally at societal level, could change negative beliefs and attitudes around HIV. Concurrently, ALHIV not accessing support groups may be reached. Furthermore, considering that pupils in classrooms include adolescents affected or living with HIV, it is vital to sensitise teachers in view of the currently used HIV curricula and teaching methodologies employed.

HIV education is the basis of HIV prevention and control, but to stop the spread of HIV, the spread of HIV-related stigma and discrimination needs to end. In light of this, intensified efforts need to promote contemporary HIV knowledge and challenge misconceptions, as well as negative stereotypes and behaviours regarding HIV since these may undermine efforts to reduce HIV onward transmission. Support groups, providing a valued avenue for ALHIV to meet peers and learn about managing HIV, could preferably include the emotional component of living with HIV, particularly in terms of the silence and secrecy as part of ALHIV's everyday life, but additionally for imparting disclosure skills, especially to intimate partners. This research exhibited that drawing was a useful tool for collecting data, however, integrating drawing as an interactive participatory learning approach could be beneficial to enhance the HIV learning experience and substitute HIV perceptions (Ainsworth et al., 2011; Van Leeuwen et al., 2015).

6.2.2 Recommendations for future research

Future research could further explore HIV perceptions among different populations, such as ALHIV, who acquired HIV behaviourally, for example through sexual intercourse, since their perceptions may differ from those of the included participants. A similar research design could be recommended, particularly with the inclusion of drawing as an arts-based data collection component. With specific consideration of the respective terminologies used for HIV, future studies involving ALHIV from rural Malawi and other countries could enhance the understanding of the preferences and learning needs in those populations in order to tailor appropriate HIV education material. Moreover, the perceptions of ALHIV not accessing support groups or hospital care could illuminate on how far the exposure to hospital HIV books contributed to the findings of the current study. Furthermore, the HIV perceptions of adult PLHIV and adolescents not living with HIV in regard to pictorial HIV representations and the language used for HIV could widen the understanding of the extent of the phenomenon, which may guide the development of future HIV education. Additionally, comparing HIV perceptions of ALHIV adherent to ART with those not adherent to ART may - despite facing similar challenges - illuminate distinct HIV perceptions. Also, the HIV perceptions of caregivers, healthcare workers and teachers could provide a greater variety of perspectives in order to steer a multidisciplinary approach when aiming for novel and appropriate care strategies. Further research could also investigate differences between school HIV lessons and HIV education received at hospitals for being able to align the knowledge base of those living with HIV and their HIV-negative peers and to explore whether this alignment would have an impact on HIV-related stigma and discrimination. Finally, as the data were collected with a follow-up after 2-4 weeks, a further follow-up after a longer period may present changes in the participants' HIV perceptions. Concerning research designs, large scale mixed-methods or quantitative studies could use surveys regarding HIV

perceptions to explore the causal factors of HIV perceptions, to allow the generalisation of findings and to inform the development of effective interventions.

6.3 Reflections on the research project

This PhD journey was a revelation for the research participants and myself as researcher with regards to the different ways HIV can be imagined and understood, as well as the meanings attached to these perceptions. From the beginning, the plan of integrating drawings as one of the data collection methods proved to be beneficial to gain a visual perspective of ALHIV's resourceful HIV perceptions. However, challenges, such as the need to change the research setting and the employment of an additional recruitment strategy required negotiations, amendments of the ethical approvals and flexibility regarding the approaches initially envisioned. Reflecting on those modifications allowed a deeper insight of the multiple capacities of a researcher. Additionally, the IDIs, including the drawing activity and the FGDs had a planned duration of approximately 60 minutes each. However, the duration of discussions was often extended with IDIs ranging from 50-140 minutes, FGDs with ALHIV 90-165 minutes and the FGD with service providers took 130 minutes. These unplanned, prolonged conversations were based on participants' demand and appreciation of using this quality time for discussing HIV openly in a safe space, which provided a wider understanding of the realities the participants were eager to share. Furthermore, the continuous reflexivity regarding the researcher's own emotions and conceptions was essential on a personal level, but also to ensure that this study was conducted in line with ethical principles and quality standards through justifications for each of the steps undertaken in the research project. Being able to give a voice to the often ignored ALHIV made me feel grateful and I hope that their voices are appreciated beyond the academic audience, creating an impact in a practical way to improve their realities of living with HIV.

6.4 Conclusion

This phenomenological study has contributed to the understanding of the diverse HIV perceptions among ALHIV in Malawi. The findings illustrate the tensions between HIV educational stances, the sources of HIV perceptions and their influence on the emotional wellbeing of the ALHIV population. The recommendations for practice highlight the need for reviewing and evaluating current HIV educational material at schools, communities and hospitals to enhance health literacy and emotional wellbeing, and reduce HIV-related stigma and discrimination.

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APPENDICES

Appendix 1. Key terms employed for database search

Adolescents	HIV	Sub-Saharan Africa	Perception
Adolescen* OR Youth* OR Teen* OR Juvenile* OR Minor* OR "Young person*" OR OR Child* OR P?ediatric*	HIV OR "Human Immuno?deficiency Virus" OR AIDS OR "Acquired Immuno?deficiency Syndrome" OR "HIV Virus" OR "HIV-Virus"	"Sub?Saharan Africa" OR SSA OR "Africa South of the Sahara" OR Angola OR Benin OR Botswana OR "Burkina Faso" OR Burundi OR Cameroon OR "Cape Verde" OR "Central African Republic" OR Chad OR Comoros OR Congo OR Djibouti OR "Equatorial Guinea" OR Eritrea OR Ethiopia OR Gabon OR Gambia OR Ghana OR Guinea OR Guinea-Bissau OR Kenya OR Lesotho OR Liberia OR Madagascar OR Malawi OR Mali OR Mauritania OR Mauritius OR Mozambique OR Namibia OR Niger OR Nigeria OR Reunion OR Rwanda OR "Sao Tome and Principe" OR Senegal OR Seychelles OR "Sierra Leone" OR Somalia OR "South Africa" OR "South Sudan" OR Sudan OR Swaziland OR Eswatini OR Tanzania OR Togo OR Uganda OR Zambia OR Zimbabwe	Perception* OR "Illness perception*" OR "Illness representation" OR "Illness cognition" OR "Illness identity" OR Belief* OR "Common sense model" OR "Emotional representation*" OR "Cognitive representation*" OR "Concept* of HIV" OR "Self regulation theory" OR "Pictorial Representation"
Adolescence [MeSH term]	"HIV" [MeSH term] OR "AIDS" [MeSH term]	"Africa South of the Sahara" [MeSH term]	Perception [MeSH term] OR "Illness Perception" [MeSH term]

Appendix 2. Quality appraisal of qualitative studies (CASP checklist)

Section	A: Are the results of the study valid?					B: What are the results?				C: Will the results help locally?
	Q 1 Was there a clear statement of the aims of the research?	Q 2 Is a qualitative methodology appropriate?	Q 3 Was the research design appropriate to address the aims of the research?	Q 4 Was the recruitment strategy appropriate to the aims of the research?	Q 5 Was the data collected in a way that addressed the research issue?	Q 6 Has the relationship between researcher and participants been adequately considered?	Q 7 Have ethical issues been taken into consideration?	Q 8 Was the data analysis sufficiently rigorous?	Q 9 Is there a clear statement of findings?	Q 10 How valuable is the research?
Reference										
Adams & Crowley, 2021	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Abubakar et al., 2016	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Appiah et al., 2019	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Ashaba et al., 2019	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Bernays et al., 2015	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Busza et al., 2013	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Callen et al., 2022	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Chory et al., 2021	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Crowley et al., 2019	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Dako-Gyeke et al., 2020	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Daniel, 2015	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Denison et al., 2015	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Doat et al., 2021	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Gitahi et al., 2020	Y	Y	Y	Y	Y	N	Y	Y	Y	Y

Section	A: Are the results of the study valid?					B: What are the results?				C: Will the results help locally?
	Q 1 Was there a clear statement of the aims of the research?	Q 2 Is a qualitative methodology appropriate?	Q 3 Was the research design appropriate to address the aims of the research?	Q 4 Was the recruitment strategy appropriate to the aims of the research?	Q 5 Was the data collected in a way that addressed the research issue?	Q 6 Has the relationship between researcher and participants been adequately considered?	Q 7 Have ethical issues been taken into consideration?	Q 8 Was the data analysis sufficiently rigorous?	Q 9 Is there a clear statement of findings?	Q 10 How valuable is the research?
Reference										
Horns Schuh et al., 2014	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
James et al., 2018	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Katirayi et al., 2021	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Kawuma et al., 2014	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Kimera et al., 2020a	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Kimera et al., 2020b	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Knizek et al., 2017	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Kunapareddy et al., 2014	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Lanyon et al., 2020	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Li et al., 2010	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Loos et al., 2013	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Luseno et al., 2017	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Mackworth-Young et al., 2017	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Mackworth-Young et al., 2021	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Madiba & Mokgatle, 2016	Y	Y	Y	Y	Y	N	Y	Y	Y	Y

Section	A: Are the results of the study valid?					B: What are the results?				C: Will the results help locally?
	Q 1 Was there a clear statement of the aims of the research?	Q 2 Is a qualitative methodology appropriate?	Q 3 Was the research design appropriate to address the aims of the research?	Q 4 Was the recruitment strategy appropriate to the aims of the research?	Q 5 Was the data collected in a way that addressed the research issue?	Q 6 Has the relationship between researcher and participants been adequately considered?	Q 7 Have ethical issues been taken into consideration?	Q 8 Was the data analysis sufficiently rigorous?	Q 9 Is there a clear statement of findings?	Q 10 How valuable is the research?
Reference										
Madiba & Josiah, 2019	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Maseko & Madiba, 2020	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Mattes, 2014	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Mburu et al., 2014a	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Mburu et al., 2014b	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
McHenry et al., 2017	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Midtbø et al., 2012	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Mupambireyi et al., 2014	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Mutumba et al., 2015	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Mutumba et al., 2019	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Otieno & Obuya, 2019	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Petersen et al., 2010	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Phuma-Ngaiyaye & Dartey, 2015	Y	Y	Y	Y	Y	N	Y	Y	Y	Y

Section	A: Are the results of the study valid?					B: What are the results?				C: Will the results help locally?
	Q 1 Was there a clear statement of the aims of the research?	Q 2 Is a qualitative methodology appropriate?	Q 3 Was the research design appropriate to address the aims of the research?	Q 4 Was the recruitment strategy appropriate to the aims of the research?	Q 5 Was the data collected in a way that addressed the research issue?	Q 6 Has the relationship between researcher and participants been adequately considered?	Q 7 Have ethical issues been taken into consideration?	Q 8 Was the data analysis sufficiently rigorous?	Q 9 Is there a clear statement of findings?	Q 10 How valuable is the research?
Reference										
Pienaar & Visser, 2012	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Thupayagale-Tshweneagae, 2010	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Van der Merwe & van der Merwe, 2020	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Willis et al., 2018	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Woollett et al., 2017	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Yang et al., 2018	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Zanoni et al., 2020	Y	Y	Y	Y	Y	N	Y	Y	Y	Y

Appendix 3. Quality appraisal of mixed-methods studies (MMAT – version 2011)

	Questions	Enimil et al., 2016	Kaunda-Khangamwa et al., 2020	Mavhu et al., 2013	Okawa et al., 2017
Screening questions (for all types)	Are there clear qualitative and quantitative research questions (or objectives*), or a clear mixed methods question (or objective*)?	Yes	Yes	Yes	Yes
	Do the collected data allow address the research question (objective)? E.g., consider whether the follow-up period is long enough for the outcome to occur (for longitudinal studies or study components).	Yes	Yes	Yes	Yes
5. Mixed methods	5.1. Is the mixed methods research design relevant to address the qualitative and quantitative research questions (or objectives), or the qualitative and quantitative aspects of the mixed methods question (or objective)?	Yes	Yes	Yes	Yes
	5.2. Is the integration of qualitative and quantitative data (or results*) relevant to address the research question (objective)?	Yes	Yes	Yes	Yes
	5.3. Is appropriate consideration given to the limitations associated with this integration, e.g., the divergence of qualitative and quantitative data (or results*) in a triangulation design?	Yes	Yes	Yes	Yes

Appendix 4. Quality appraisal of quantitative study (Checklist for Cross-Sectional Studies by Joanna Briggs Institute)

	Reference
	Lawan et al., 2015
Q 1: Were the criteria for inclusion in the sample clearly defined?	Yes
Q 2: Were the study subjects and the setting described in detail?	Yes
Q 3: Was the exposure measured in a valid and reliable way?	Yes
Q 4: Were objective, standard criteria used for measurement of the condition?	Yes
Q 5: Were confounding factors identified?	Not applicable
Q 6: Were strategies to deal with confounding factors stated?	Not applicable
Q 7: Were the outcomes measured in a valid and reliable way?	Yes
Q 8: Was appropriate statistical analysis used?	Yes

Appendix 5. Characteristics of studies included in the systematic literature review

#	Author/s	Study Design	Context and setting	Year study conducted	Participants	Research aim/question
1	Abubakar et al., 2016	Qualitative: IDIs	At the Centre for Geographic Medicine Research-Coast in Kilifi, Kenya Urban/rural: Not mentioned	Not mentioned	44 participants (12 HIV+, 7 HIV-) 12 ALHIV aged 12–17 years (mean age: 14.50 years) 3 female, 9 male Mode of HIV acquisition: Perinatal Other participants: HIV-negative adolescents, caregivers, healthcare workers, teachers	To explore lived experiences and the challenges faced by ALHIV in the African context.
2	Adams & Crowley, 2021	Qualitative: IDIs	At 2 primary clinics in South Africa	Not mentioned	13 ALHIV aged 14-19 years Gender: no information Mode of HIV acquisition: 11 perinatally, 2 behaviourally	To explore the self-management needs of ALHIV.
3	Appiah et al., 2019	Qualitative interpretative phenomenological design: IDIs	12 antiretroviral treatment (ART) centres in Northern and Southern Ghana Rural + urban	January 2017 to June 2018	30 disclosed ALHIV aged 9–19 years (mean age: 14 years) 17 female, 13 male Mode of HIV acquisition: Not mentioned	To explore children's HIV disclosure experiences.
4	Ashaba et al., 2019	Qualitative: IDIs FGDs	Mbarara, a district of southwestern Uganda Rural	February to May 2016	20 ALHIV aged 13-17 years 15 female, 5 male Mode of HIV acquisition: Not mentioned Other participants: Adult female caregivers	To understand psychosocial challenges and their effects on mental health and HIV treatment outcomes.
5	Bernays et al., 2015	Qualitative: FGDs IDIs	2 countries: 3 sites in Uganda and 1 in Zimbabwe Urban/rural: Not mentioned	2011 to 2013	104 ALHIV aged 11-13 years, 58 female, 46 male Mode of HIV acquisition: Perinatal Other participants: Caregivers, healthcare workers	To describe how children articulate 'living with' and 'growing up' with HIV and how this is shaped through their relationships with the adults around them.
6	Busza et al., 2013	Qualitative: IDIs FGDs	Dar es Salaam (urban) and Tanga (rural) Tanzania	January to March 2011	14 ALHIV aged 15–19 years 5 female, 9 male Mode of HIV acquisition: Perinatal Other participants: Caregivers, volunteer home-based care providers	To explore how adolescents living with HIV experience their nascent sexuality as part of an evaluation of a home-based care programme.

#	Author/s	Study Design	Context and setting	Year study conducted	Participants	Research aim/question
7	Callen et al., 2022	Qualitative: IDIs	2 sites: 1 urban and 1 peri-urban site in Western Kenya	Not mentioned	46 ALHIV aged 14-19 years 21 female, 25 male Mode of HIV acquisition: Perinatal	To understand adolescents' experiences with stigma, how they understand the stigmatizing beliefs of others, and how these experiences impact their ongoing perception of stigma.
8	Chory et al., 2021	Qualitative: Use of WhatsApp® chat transcripts	Western Kenya Urban + rural	Not mentioned	30 ALHIV aged 10-19 years on ART (mean age: 15.4 years) 17 female, 13 male Mode of HIV acquisition: Not mentioned	To examine and characterize the HIV-related knowledge, attitudes and beliefs, behaviours, and experiences of ALHIV revealed in the contextual data from their WhatsApp group chats.
9	Crowley et al., 2019	Qualitative: IDIs FGDs	South Africa 2 facilities Urban	Not mentioned	44 ALHIV aged 13-18 years 26 female, 18 male Mode of HIV acquisition: Perinatal Other participants: Caregivers, healthcare workers	To explore HIV self-management from the perspectives of adolescents, caregivers, and HCW.
10	Dako-Gyeke et al., 2020	Qualitative: IDIs	Adolescent HIV clinic in the Korle-Bu Teaching Hospital, Accra, Ghana Urban	Not mentioned	30 ALHIV aged 12-19 years 17 female, 13 male Mode of HIV acquisition: Not mentioned	To explore the experiences of adolescents living with HIV.
11	Daniel, 2015	Qualitative: IDIs	HIV treatment centre in Iringa, Tanzania Urban	Not mentioned	13 ALHIV aged 10-15 years 6 female, 7 male Mode of HIV acquisition: Not mentioned Other participants: Healthcare workers	To explore how HIV-positive children respond to: (1) the disclosure process; and (2) the perceived need for secrecy and silence concerning living with HIV.
12	Denison et al., 2015	Qualitative: IDIs	Copperbelt Province of Zambia in 2 ART clinics in Ndola, Zambia Urban	December 2011 to February 2012	32 ALHIV aged 15-18 years 16 female, 16 male Mode of HIV acquisition: 81% perinatal Other participants: Caregivers	To explore ART adherence from the perspectives and experiences of older ALHIV and their adult caregivers in Zambia.
13	Doat et al., 2021	Qualitative Phenomenological study: IDIs	Tamale Teaching Hospital, in Tamale, Northern Ghana Urban/rural not mentioned	September 2019 to January 2020	12 ALHIV aged 14–19 years 8 female, 4 male Mode of HIV acquisition: 9 perinatal, 3 sexual	To explore the meaning of living as an adolescent with HIV in Ghana.
14	Enimil et al., 2016	Mixed-methods: Quantitative questionnaire IDIs	HIV clinic in Kumasi, Ghana Urban	Not mentioned	40 ALHIV aged 12–19 years 20 female, 20 male Mode of HIV acquisition: Perinatal 67% not virally suppressed	To examine the challenges and protective factors for ALHIV within the sociocultural context of Ghana. Specific domains assessed included quality of life, physical/medical health, psychological wellbeing, and social relationships.
15	Gitahi et al., 2020	Qualitative: IDIs FGDs	In 2 high-volume urban HIV clinics: Mbagathi Hospital and Kenyatta Hospital Nairobi, Kenya	December 2017 to December 2018	58 ALHIV aged 16–19 years 25 female, 33 male Mode of HIV acquisition: Perinatal	To explore the circumstances surrounding the phenomena disclosure process, post-disclosure emotional experiences, expectations and informational needs of older ALHIV during the transition to adult care.

#	Author/s	Study Design	Context and setting	Year study conducted	Participants	Research aim/question
1 6	Hornschuh et al., 2014	Qualitative: FGDs	At the Pennatal HIV Research Unit located at the Chris Hani Baragwanath Hospital in Soweto, South Africa Urban	March to July 2012	18 patients aged 15-25 years 13 female, 5 male Mode of HIV acquisition: 11 perinatal, 4 sexual, 3 unknown	To assist with creating a better understanding of the experiences of ALHIV in care. To elicit perspectives about the clinic and the staff, ideas for improvements, and opinions about clinic transfer.
1 7	James et al., 2018	Qualitative: IDIs	North West Province, South Africa Peri-urban area	October 2015	15 ALHIV aged 15–19 years 10 female, 5 male Mode of HIV acquisition: Not mentioned Other participants: Healthcare workers, facility managers	To explore the perceptions of healthcare providers and the experiences of ALHIV.
1 8	Katirayi et al., 2021	Qualitative: FGDs	Lusaka, Zambia and Kisumu, Kenya Urban	November 2016	88 ALHIV aged 15–19 years old (Lusaka: 53, Kisumu: 35) 50 female, 38 male Mode of HIV acquisition: Not mentioned Other participants: Adolescents with unknown HIV status	To explore perceptions about HIV testing and treatment among adolescents living with HIV and adolescents of unknown HIV status.
1 9	Kaunda-Khangamwa et al., 2020	Mixed-methods: Quantitative: Survey Qualitative: IDIs	ART and teen-club clinic in Blantyre, Malawi Urban	November 2018 to June 2019	406 ALHIV aged 15-19 years in quantitative study 4 ALHIV aged 15-19 years in case study 2 female, 2 male Mode of HIV acquisition: Not mentioned	To examine the experiences of ALHIV as influenced by age, gender and the utilisation (or not) of health services.
2 0	Kawuma et al., 2014	Qualitative: IDIs	Entebbe in Uganda Urban	July 2011 to November 2012	26 ALHIV aged 11-13 years 12 female, 14 male Mode of HIV acquisition: Not mentioned Other participants: Caregivers, healthcare workers	To describe how the experience of life-long HIV and ART interplays with everyday life for young adolescents within the different care environments such as the home, in the clinic and at school.
2 1	Kimera et al., 2020a	Qualitative: IDIs	In 3 health facilities in Western Uganda Urban/rural: not mentioned	July to October 2018	35 ALHIV aged 12–19 years (mean age: 16,2 years) 16 female, 19 male Mode of HIV acquisition: 88% perinatal	To understand the barriers and facilitators for ALHIV in Uganda to attend school.
2 2	Kimera et al., 2020b	Qualitative: Photovoice FGDs	A regional referral hospital in Kabarole district, Western Uganda Urban/rural: Not mentioned	September to October 2018	11 ALHIV aged 15–19 years 6 female, 5 male Mode of HIV acquisition: 82% perinatal	To explore the lived experiences of ALHIV with HIV-related stigma.

#	Author/s	Study Design	Context and setting	Year study conducted	Participants	Research aim/question
2 3	Knizek et al., 2017	Qualitative: IDIs	Urban and rural Uganda	Not mentioned	21 ALHIV aged 12-17 years 12 female, 9 male Mode of HIV acquisition: Not mentioned	To investigate both the protective and the risk factors in ALHIVs' care environment in order to understand what might contribute to negative outcomes and what might provide a protective buffer against harmful life events.
2 4	Kunapareddy et al., 2014	Qualitative: IDIs FGDs	At an urban and rural clinic site in western Kenya	March to November 2007	23 ALHIV aged 10-16 years (mean age: 13,2 years) 11 female, 12 male Mode of HIV acquisition: Perinatal	To identify key factors identified by ALHIV on ART as contributing to medication adherence in western Kenya.
2 5	Lanyon et al., 2020	Qualitative study in-depth, semi-structured interviews	HIV clinic in Kampala, Uganda Urban	2017 to 2018	20 ALHIV aged 10-18 years, all experienced treatment failure and recently transitioned to second-line therapy 8 female, 12 male Mode of HIV acquisition: Perinatal	To explore the knowledge and skills adolescents need in order to maintain improved adherence behaviours, and the specific ways clinicians and caregivers may support young people to do so more independently.
2 6	Lawan et al., 2015	Quantitative descriptive cross-sectional design: Questionnaires	Murtala Muhammad Specialist Hospital/ART clinic in Kano, northwestern Nigeria Urban/rural: Not mentioned	June/July 2014	371 ALHIV aged 10-19 years (mean age: 14.9 years) 219 female, 181 male Mode of HIV acquisition: Not mentioned	To determine the psychosocial challenges faced by ALHIV and how these challenges influence their adherence to ART.
2 7	Li et al., 2010	Qualitative: FGDs	Family HIV clinic at Tygerberg Academic Hospital in Cape Town, South Africa Urban	Not mentioned	26 ALHIV aged 10-15 years (mean age: of 12.5 years) 10 female, 16 male Mode of HIV acquisition: 16 perinatal, 2 sexual, 8 unknown	To identify the experiences and needs of adolescents growing up in care or on treatment for HIV.
2 8	Loos et al., 2013	Qualitative: FGDs	2 countries: Kisumu, Western Kenya and Greater Kampala, Uganda Urban/rural: not mentioned	July to November 2009	119 ALHIV aged 10–19 years 64 female, 55 male Mode of HIV acquisition: 43% unknown, from remaining: 78% perinatally Other participants: Caregivers, healthcare workers	To assess the impact of HIV and related contextual conditions on identity formation of ALHIV in the domains of physical, cognitive, social, and sexual development.
2 9	Luseno et al., 2017	Qualitative: IDIs	A high prevalence rural setting in Siaya county, western Kenya	April to November 2014	29 ALHIV (aged 15–19) 16 female, 13 male Mode of HIV acquisition: 21 perinatal, 7 sexual, 1 unclear Other participants: Caregivers	To describe adolescents' experiences with HIV services at different stages of the care continuum: HIV testing, linkage to care, and retention in treatment.

#	Author/s	Study Design	Context and setting	Year study conducted	Participants	Research aim/question
30	Mackworth-Young et al., 2017	Qualitative: Grounded theory IDIs Participatory workshops (concept mapping, collages and vignettes)	2 urban, government health facilities in Lusaka, Zambia	January to April 2015	24 ALHIV aged 15-18 years 24 female Mode of HIV acquisition: 17 perinatal	To explore the messaging and restrictions imposed on adolescent girls living with HIV in Zambia.
31	Mackworth-Young et al., 2021	Qualitative: IDIs Participatory workshops	Lusaka, Zambia 2 centres Urban	2014 to 2015	24 ALHIV aged 15-19 years 24 female Mode of HIV acquisition: 17 perinatal, 2 sexual abuse, 5 not specified	To understand how HIV impacted the experiences of ALHIV over time.
32	Madiba & Mokgatle, 2016	Qualitative: IDIs	Health facilities in Mpumalanga and Gauteng provinces, South Africa Urban-rural mix	December 2012 to July 2013	37 ALHIV aged 12-18 years 22 female, 15 male Mode of HIV acquisition: Perinatal	To explore how ALHIV experience living as HIV positive adolescents and to examine their perceptions and experiences about disclosure and onward self-disclosure to friends, sexual partners, and others.
33	Madiba & Josiah, 2019	Qualitative: IDIs	At the infectious disease control centre in a multispecialty tertiary care and teaching hospital in Francistown, Botswana Urban/rural: Not mentioned	October 2015 to January 2016	30 ALHIV aged 12 to 19 years (mean age: 15.7 years), all disclosed, 16 started second-line treatment 13 female, 17 male Mode of HIV acquisition: Perinatal	To assess self-reported medication adherence among ALHIV and explore structural factors that hinder or motivate them to adhere to ART.
34	Maseko et al., 2020	Qualitative: IDIs	2 primary health care facilities located in a rural health district in Mpumalanga Province, South Africa	Not mentioned	21 ALHIV aged 12–19 years (mean age: 15.9 years), all disclosed 14 female, 7 male Mode of HIV acquisition: Perinatal	To describe the experiences of adolescents with perinatal HIV in regard to disclosure, and to examine the impact disclosure has on their emotional health and behaviours.
35	Mattes, 2014	Qualitative: IDIs Photo elicitation interviews Participant observation	HIV treatment centers, two orphanages, and children's homes in Tanga north-eastern Tanzania Urban/rural: Not mentioned	September 2008 to September 2011	13 ALHIV aged 9-19 years 5 female, 8 male Mode of HIV acquisition: Not mentioned Other participants: Caregivers	To explore the subjective experiences of children and adolescents living with antiretroviral medicines.

#	Author/s	Study Design	Context and setting	Year study conducted	Participants	Research aim/question
3 6	Mavhu et al., 2013	Mixed-methods: Quantitative questionnaire Qualitative: IDIs FGDs Life history narratives "Rivers of life"	Harare, Zimbabwe Urban	July to August 2009	Quantitative: 229 ALHIV aged 6-19 years (median age:14 years) 135 female, 94 male Qualitative: 56 ALHIV aged 15-18 years Gender: no information Mode of HIV acquisition: Not mentioned Other participants: Caregivers, healthcare workers, community members	To describe the lived experiences of HIV positive young people and their caregivers in Zimbabwe.
3 7	Mburu et al., 2014a	Qualitative: IDIs FGDs	In 1 rural site (Kalomo) and 2 urban sites (Kitwe, Lusaka) across Zambia	April to December 2010	58 ALHIV aged 10-19 years (mean age:16,8 years) 29 female, 29 male Mode of HIV acquisition: Not mentioned Other participants: Caregivers, healthcare workers	To explore the disclosure of HIV status to ALHIV, adolescents' disclosure of their status to others; and the impact of both forms of disclosure on adolescents.
3 8	Mburu et al., 2014b	Qualitative: IDIs FGDs	In 1 rural district (Kalomo) and 2 urban districts (Kitwe and Lusaka) in Zambia	April to December 2010	58 ALHIV aged 10-19 years 29 female, 29 male Mode of HIV acquisition: Not mentioned Other participants: Caregivers, healthcare workers	To examine the experiences of adolescents living with HIV.
3 9	McHenry et al., 2017	Qualitative: FGDs	AMPATH HIV clinics in western Kenya Urban + rural	February to April 2014	39 ALHIV aged 10-15 years (mean age: 13) 28 female, 11 male Mode of HIV acquisition: Not mentioned Other participants: Caregivers	To characterize how ALHIV understood, experienced, and were impacted by HIV stigma as well as their perspectives on how to measure and intervene to reduce HIV stigma.
4 0	Midtbø et al., 2012	Qualitative: IDIs FGDs	2 countries: Botswana: (2 sites: a hospice in an urban setting and a hospital in a rural setting) Tanzania within an organisation called 'Pastoral Activities and Services for people with AIDS' in urban Dar es Salaam	June to September 2011	28 ALHIV aged 12-19 years; 17 female, 11 male Botswana: N=16, aged 12-19 years; 10 female, 6 male Tanzania: N=12 aged 12-14 years; 7 female, 5 male Mode of HIV acquisition: Not mentioned Other participants: Healthcare workers	To understand and identify the pathways between HIV-status disclosure, ART, and children's psychosocial wellbeing.

#	Author/s	Study Design	Context and setting	Year study conducted	Participants	Research aim/question
4 1	Mupambireyi et al., 2014	Qualitative: IDIs FGDs	Harare, Zimbabwe Urban	October 2011 to December 2012	26 ALHIV aged 11–13 years 14 female, 12 male Mode of HIV acquisition: Perinatal Other participants: Caregivers	To explore peer social support experiences of HIV-perinatally infected children in Harare.
4 2	Mutumba et al., 2015	Qualitative: IDIs	A large HIV treatment center in Kampala, Uganda Urban	August to November 2011	38 ALHIV aged 13-19 years 20 female, 18 male Mode of HIV acquisition: Perinatal	To identify the psychosocial challenges and coping strategies among perinatal HIV-infected adolescents.
4 3	Mutumba et al., 2019	Qualitative FGDs	Kampala, Uganda Urban	Not mentioned	34 ALHIV aged 12-19 years 17 female, 15 male Mode of HIV acquisition: Not mentioned Other participants: Caregivers, healthcare workers	To describe ALHIV's perceptions of HIV self-management roles, in order to provide suggestions on strategies for improving ALHIV's self-management and indicate their preferences regarding the following intervention approaches: group or peer support, individual counselling, joint parent-adolescent counselling, and eHealth technologies.
4 4	Okawa et al., 2017	Mixed-methods: Structured questionnaire including two open-ended questions	At the University Teaching Hospital in Lusaka, Zambia Urban	April to July 2014	190 ALHIV aged 15–19 years 110 female, 80 male Mode of HIV acquisition: Not mentioned	To examine the setting of HIV serostatus disclosure for adolescents, its impacts on them, and their suggestions on the best practice of HIV disclosure.
4 5	Otieno & Obuya, 2019	Qualitative: Phenomenological study IDIs	In one of the slums in Nairobi, Kenya Urban	January to April 2015	6 ALHIV aged 10-19 years Gender: Not mentioned Mode of HIV acquisition: Not mentioned Other participants: Caregivers, social worker, clinician	To examine the communication experiences of adolescents living with HIV/AIDS and their perceptions of these experiences.
4 6	Petersen et al., 2010	Qualitative: IDIs	Urban-based hospital in the city of Durban in the KwaZulu-Natal province of South Africa	January 2008	25 ALHIV aged 14-16 years, 16 orphans 12 female, 13 male Mode of HIV acquisition: Not mentioned Other participants: Caregivers	To develop an understanding of the psychosocial challenges as well as protective influences promoting socio-emotional coping in HIV+ adolescents.
4 7	Phuma-Ngaiyaye & Dartey, 2015	Qualitative: IDIs	Paediatric HIV clinic at Mzuzu, Malawi Urban	Not mentioned	10 ALHIV aged 10-14 years 5 female, 5 male Mode of HIV acquisition: Not mentioned Other participants: Caregivers	To explore the experiences of children living with HIV following the diagnosis disclosure.
4 8	Pienaar & Visser, 2012	Qualitative: IDIs Expressive art (drawings)	Kalafong Hospital's Paediatric HIV Clinic in Pretoria, South Africa Urban	2011	6 ALHIV aged 12-18 years 3 female, 3 male adolescents Mode of HIV acquisition: Not mentioned	To explore and describe the experiences of adolescents living with HIV that undergo chronic disease management and to describe how these experiences inform their identity.

#	Author/s	Study Design	Context and setting	Year study conducted	Participants	Research aim/question
4 9	Thupayagale-Tshweneagae, 2010	Qualitative: FGDS	In 4 day care centres in Gaborone, Botswana Urban	Not mentioned	18 ALHIV aged 13-19 years 12 female, 6 male Mode of HIV acquisition: Not mentioned	To describe adolescents' perceptions in Botswana on the behaviours that ALHIV use in dealing with stigmatization.
5 0	Van der Merwe & van der Merwe, 2020	Qualitative: IDI Draw & tell	Bloemfontein, Free State, South Africa Urban, rural: Not mentioned	Not mentioned	10 ALHIV aged 10-12 years, all disclosed 5 female, 5 male Mode of HIV acquisition: Not mentioned	To explore the understanding that children living with HIV have of their condition, and the physical and psychosocial challenges they face in pursuit of their ideals for adulthood.
5 1	Willis et al., 2018	Qualitative: IDIs Body mapping exercise	At an adolescent treatment centre in Harare, Zimbabwe Urban	January to June 2015	21 ALHIV aged 15–19 years and diagnosed with major depressive disorder 10 female, 11 male Mode of HIV acquisition: 19 perinatal	To explore the experience and manifestation of depression in ALHIV in order to inform intervention development.
5 2	Woollett et al., 2017	Qualitative: IDIs	In 5 public health clinics in Johannesburg, South Africa Urban	Not mentioned	25 ALHIV aged 13–19 years (mean age: 16 years) 15 female, 10 male Mode of HIV acquisition: Perinatal	To understand how disclosure and bereavement have an impact on perinatally infected adolescents' beliefs and understanding of their HIV infection and its management.
5 3	Yang et al., 2018	Qualitative: IDIs FGDs	Gaborone, Botswana. at the Botswana-Baylor Children's Clinical Centre of Excellence Urban	April 2014 to February 2015	47 ALHIV aged 12-19 25 female, 22 male Mode of HIV acquisition: Not mentioned Other participants: Caregivers	To explore barriers and facilitators of adherence among ALHIV who were identified as being among the best adherers and ALHIV among the worst adherers; to describe changes in adherence over time, identifying potentially modifiable risk factors for poor adherence, and elucidating the utility of different adherence monitoring strategies in adolescents on ART.
5 4	Zanoni et al., 2020	Qualitative: IDIs	In Phoenix/ KwaMashu outside of Durban, South Africa Urban, rural: Not mentioned	September 2016 to November 2017	41 ALHIV aged 14-16 years 19 female, 22 male Mode of HIV acquisition: Perinatal Other participants: Caregivers	To investigate modifiable factors to improve engagement in care prior to transition to adult care.

Appendix 6. Ethical approval by Lancaster University, Faculty of Health and Medicine Research Ethics Committee



Applicant: Nadine Ammon

Supervisor: Dr Mark Limmer

Department: Division of Health Research

FHMREC Reference: FHMREC20060

16 December 2020

Re: FHMREC20060

Perceptions and experiences of adolescents living with HIV in Malawi

Dear Nadine,

Thank you for submitting your research ethics application for the above project for review by the Faculty of Health and Medicine Research Ethics Committee (FHMREC). The application was recommended for approval by FHMREC, and on behalf of the Chair of the Committee, I can confirm that approval has been granted for this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact me if you have any queries or require further information.

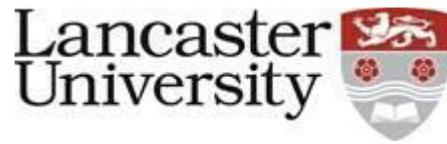
Email: fhmresearchsupport@lancaster.ac.uk

Yours sincerely,

Annie Beauchamp,

Research Ethics Officer, Secretary to FHMREC.

Appendix 7. Ethical approval by Lancaster University, Faculty of Health and Medicine Research Ethics Committee
(Amendment 1: change of research setting)



Applicant: Nadine Ammon
Supervisor: Dr Mark Limmer
Department: Division of Health Research
FHMREC Reference: FHMREC20100 (amendment to FHMREC20060)

08 February 2021

Re: FHMREC20100 (amendment to FHMREC20060)

Perceptions and experiences of adolescents living with HIV in Malawi

Dear Nadine,

Thank you for submitting your research ethics amendment application for the above project for review by the Faculty of Health and Medicine Research Ethics Committee (FHMREC). The application was recommended for approval by FHMREC, and on behalf of the Chair of the Committee, I can confirm that approval has been granted for the amendment to this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact me if you have any queries or require further information.

Email: fhmresearchsupport@lancaster.ac.uk

Yours sincerely,

Annie Beauchamp,

Research Ethics Officer, Secretary to FHMREC.

Appendix 8. Ethical approval by REC Malawi (NCST)



NATIONAL COMMISSION FOR SCIENCE & TECHNOLOGY

Lingadzi House
Robert Mugabe Crescent
P/Bag B303
City Centre
Lilongwe

Tel: +265 1 771 550
+265 1 774 189
+265 1 774 869
Fax: +265 1772 431
Email: directorgeneral@ncst.mw
Website: <http://www.ncst.mw>

NATIONAL COMMITTEE ON RESEARCH IN THE SOCIAL SCIENCES AND HUMANITIES

Ref No: NCST/RTT/2/6

11th March 2021

Ms Nadine Marita Ammon,
Principal Investigator,
C/O GIZ Health,
P.O. Box 31602,
Lilongwe 3.
Email: n.ammon@lancaster.ac.uk

Dear Ms Ammon,

RESEARCH ETHICS AND REGULATORY APPROVAL AND PERMIT FOR PROTOCOL NO. P.02/21/552: PERCEPTIONS AND EXPERIENCES OF ADOLESCENTS LIVING WITH HIV IN MALAWI

Having satisfied all the relevant ethical and regulatory requirements, I am pleased to inform you that the above referred research protocol has officially been approved. You are now permitted to proceed with its implementation. Should there be any amendments to the approved protocol in the course of implementing it, you shall be required to seek approval of such amendments before implementation of the same.

This approval is valid for one year from the date of issuance of this approval. If the study goes beyond one year, an annual approval for continuation shall be required to be sought from the National Committee on Research in the Social Sciences and Humanities (NCRSH) in a format that is available at the Secretariat. Once the study is finalised, you are required to furnish the Committee and the Commission with a final report of the study. The committee reserves the right to carry out compliance inspection of this approved protocol at any time as may be deemed by it. As such, you are expected to properly maintain all study documents including consent forms.

Wishing you a successful implementation of your study.

Yours Sincerely,

Yalonda .I. Mwanza

NCRSH ADMINISTRATOR
HEALTH, SOCIAL SCIENCES AND HUMANITIES DIVISION
For: CHAIRMAN OF NCRSH

Committee Address: *Secretariat, National Committee on Research in the Social Sciences and Humanities, National Commission for Science and Technology, Lingadzi House, City Centre, P/Bag B303, Capital City, Lilongwe3, Malawi. Telephone Nos: +265 771 550/774 869; E-mail address: ncrsh@ncst.mw*

Appendix 9. Ethical approval by FHMREC
(Amendment 2: additional recruitment strategy)



Applicant: Nadine Ammon
Supervisor: Dr Mark Limmer, Dr Sophie Patterson
Department: DHR
FHMREC Reference: FHMREC20154 (amendment to FHMREC20)

25 June 2021

Re: FHMREC20154 (amendment to FHMREC20060/FHMREC20100)
Perceptions and experiences of adolescents living with HIV in Malawi

Dear Nadine,

Thank you for submitting your research ethics amendment application for the above project for review by the Faculty of Health and Medicine Research Ethics Committee (FHMREC). The application was recommended for approval by FHMREC, and on behalf of the Chair of the Committee, I can confirm that approval has been granted for the amendment to this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact me if you have any queries or require further information.

Email: fhmresearchsupport@lancaster.ac.uk

Yours sincerely,

Tom Morley,

Research Ethics Officer, Secretary to FHMREC.

Appendix 10. Ethical approval by REC Malawi
(Amendment: additional recruitment strategy)



NATIONAL COMMISSION FOR SCIENCE & TECHNOLOGY

Lingadzi House
Robert Mugabe Crescent
P/Bag B303
City Centre
Lilongwe

Tel: +265 1 771 550
+265 1 774 189
+265 1 774 869
Fax: +265 1772 431
Email: directorgeneral@ncst.mw
Website: <http://www.ncst.mw>

**NATIONAL COMMITTEE ON RESEARCH IN THE SOCIAL
SCIENCES AND HUMANITIES**

REF.NO.NCST/RTT/2/6
9th July, 2021

Ms Nadine Marita Ammon,
Principal Investigator,
C/O GIZ Health,
P.O. Box 31602,
Lilongwe 3.
Email: n.ammon@lancaster.ac.uk

Dear Ms Ammon,

APPROVAL OF AMENDMENT TO PROTOCOL FOR PROTOCOL NO. P.02/21/552:
PERCEPTIONS AND EXPERIENCES OF ADOLESCENTS LIVING WITH HIV IN
MALAWI

The National Committee on Research Ethics in the Social Sciences and Humanities (NCRSH) reviewed your application for amendments on the participants' recruitment strategy. I am pleased to inform you that NCRSH has approved the amendments.

Please proceed with the implementation of these amendments. Thanks for your exemplary continued compliance to the principles of human subjects' protection.

Yours Sincerely,

Mike G Kachedwa

HEAD OF NCRSH SECRETARIAT

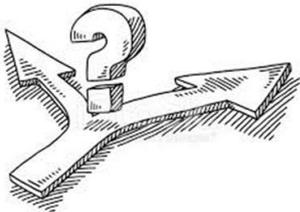
NCRSH Address: Secretariat, National Committee on Research Ethics in the Social Sciences and Humanities, National Commission for Science and Technology, Lingadzi House, City Centre, P/Bag B303, Capital City, Lilongwe3, Malawi. Telephone Nos: +265 771 550/774 869; E-mail address: ncrsh@ncst.mw

Appendix 11. Participant Information Sheet for adolescents (10-16 years, English)

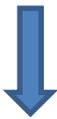


Participant Information Sheet for adolescents (10-16 years)

Title of Study: Perceptions and experiences of adolescents living with HIV in Malawi

	<p>Hello,</p> <p>My name is Nadine Ammon, I am a nurse and I like to ask you to participate in a study.</p>
<p>What is the study about?</p>	
	<p>We want to learn about your experiences and perceptions of living with HIV and how you imagine the virus.</p> <p>We do that to improve the education in the clinics to help other young people.</p>
<p>Why have I been chosen?</p>	
	<p>You have been chosen to participate because you are between 10 and 19 years old and living with HIV. We want to learn more about your experiences so that we can improve education materials used in our clinics and elsewhere.</p>
<p>Do I have to take part?</p>	
	<p>No. It's completely up to you. You can stop taking part at any time, and you do not need to share information you don't want to. Your decision will not change the way you are cared for at the clinic.</p>

What will I be asked to do if I take part?



+265 992 273 433

If you would like to participate in the study, you will receive an information sheet for your parents or caregivers. You can then talk to your caregiver about the study and when you both agree, you can call me, so that we can arrange a meeting where you can get more information. You will then be asked to sign an assent form.

For the study, you will come to the peer support group at [REDACTED] clinic, which you are already attending. This is where the study will take place.

You will come on three days for two interviews and one group discussion which will each take about 1 hour. In the first meeting I will ask you about your experiences and I will ask you to draw a picture. Don't worry, you don't need to be an artist for that activity. In the second meeting we will talk about our discussion of the first meeting and how we could improve the HIV education material. During the group discussion there will be three more participants and you will be asked to discuss questions. The date and time of the interviews will be arranged with you, so that it does not disturb your daily schedule. You will be interviewed by me and a [REDACTED] clinic staff member will help with translations.

We will ask you to audio record our discussion, so that I can remember what we talked about. If you would like to keep the drawing, you will receive it after I have made a scan of it.

Will other people know what I have said?



Everything you tell me in the interviews will be confidential. The interviews will be typed, and your name will be removed so that nobody can identify you in this information.

What will happen afterwards?



I will write a report about our discussions and I may attach a photo of your drawing. Your name will not be used. There might be an exhibition of the drawings that were produced by all participants. If this takes place you will receive an invitation to come and see the different drawings there.

Are there any risks?



There are no expected risks. But if you experience any worry or distress during or after participation you can inform me, so that I can help you. You can also contact one of the following telephone numbers:

- Tithandizane National Child Helpline. Please dial: 116
- Teen Support Line. Please dial: 53535

Are there any benefits to taking part?



Although you may find participating interesting, there are no direct benefits in taking part. Through the information you will share, HIV education material might be improved. Refreshments will be provided during the group discussions and you will receive 2.000MK as transport reimbursement.

Where can I get more information about the study?



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

Nadine Ammon
E-mail: n.ammon@lancaster.ac.uk
Telephone: +265 992 273 433



Thank you for reading this information sheet!



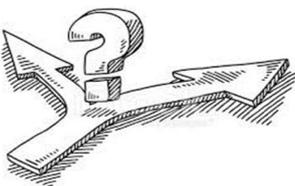
Appendix 12. Participant Information Sheet for adolescents (10-16 years, Chichewa)



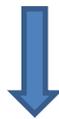
Chifomu cha otenga nawo mbali cha achinyamata

(a zaka zapakati pa 10 mpaka 16)

Mutu wa kafukufuku: Malingaliro ndi m'mene akukhalira achinyamata amene ali ndi kachilombo ka HIV ku Malawi.

	<p>Hello, Dzina langa ndine Nadine Ammon. Ndine namwino ndipo ndikufuna kukupemphani kuti mutenge nawo mbali mu kafukufuku.</p>
<p>Kodi kafukufukuyu ndi okhudzana ndi chiyani?</p>	
	<p>Tikufuna kudziwa za m'mene mukukhalira ndi kachilombo ka HIV ndi malingaliro anu komanso ndi m'mene mumaganizira za maonekedwe a kachilomboka. Tikupanga izi kuti tipititse patsogolo maphunziro a kachilombo ka HIV mu zipatala kuti zithandize achinyamata ena.</p>
<p>Kodi ndasankhidwa chifukwa chiyani?</p>	
	<p>Mwasankhidwa kuti mutenge nawo mbali mu kafukufukuyu chifukwa muli ndi zaka zakubadwa za pakati pa 10 ndi 19 ndipo mukukhala ndi kachilombo ka HIV. Tikufuna tidziwe zambiri za m'mene mukukhalira ndi zimene mukukumana nazo kuti tithe kupititsa patsogolo mabuku amene timaphunzitsira mu zipatala zathu ndi kwina kulikonse.</p>
<p>Kodi ndikuyenera kutengapo mbali?</p>	
	<p>Ayi. Zikutengera inuyo kwathunthu. Mukhoza kusiya kutengapo mbali pa nthawi ina ili yonse ndipo simukuyenera kufotokoza zinthu zimene simukufuna. Chisankho chanu sichidzakhudza chisamaliro chimene mukulandira ku chipatala.</p>

Kodi ndidzafunsidwa kuti nditani ndikasankha kutenga nawo mbali mu kafukufukuyu?



+265 992 273 433

Ngati mukufuna kutenga nawo mbali mu kafukufukuyu mudzapatsidwa chifomu cha makolo anu kapena omwe amakusamalirani. Mukhoza kukambirana ndi omwe amakusamalirani za kafukufukuyu ndipo mukagwirizana mukhoza kundiimbira kuti ndikonze zoti tidzakumane ndi cholinga choti mudzamvetsetse zambiri zokhudzana ndi kafukufukuyu. Ndipo mudzafunsidwa kudzasayina chifomu cha chilolezo. Kafukufukuyu adzapangidwira ku chipatala cha [REDACTED] komwe mumapita ndikale choncho mudzayenera kubwera ku chipatala. Uku ndi kumene kafukufukuyu adzachitikire. Mudzabwera kwa masiku atatu kuti mudzafunsidwe mafunso kawiri panokha ndipo kachitatu pa gulu, izi zizidzatenga ola limodzi limodzi. Pa kukumana kwathu koyamba ndidzakufunsani za m'mene mukukhalira ndi kachilombo ka HIV ndipo ndidzakufunsani kuti mujambule chithunzi. Musadandaule chifukwa simukuyenera kukhala katswiri wojambula kuti mudzathe kupanga izi. Pakukumana kwathu kwachiwiri tidzakambirana zomwe tidakambirana pa kukumana kwathu koyamba ndipo ndi m'mene tingapititsire patsogolo mabuku athu ophunzitsira za kachilomboka. Pa kukumana kwathu kwa m'magulu padzakhala otenga nawo mbali apadera atatu ndipo mudzapemphedwa kuti mukambirane mafunso. Nthawi ndi tsiku la kafukufukuyu zidzakhazikitsidwa ndi inu kuti zisasokoneze zochita zanu za tsiku ndi tsiku. Mudzafunsidwa mafunso ndi ine ndi m'modzi mwa anthu ogwira ntchito ku chipatala cha [REDACTED] amene adzathandizire kutanthauzira. Tidzakupemphani kuti tijambule mawu ndi makina ojambulira kuti ndidzathe kukumbukira zimene tidzakambirana. Ngati mungafune kusunga zithunzi zojambula mudzalandira ndikaziunika ndi kuziona.

Kodi anthu ena adzadziwa zimene ndidzafotokoze?



Chili chonse chimene mudzandifotokozere chidzakhala cha chinsinsi. Zokambirana zathuzi zidzatayipidwa koma dzina lanu lidzachotsedwa choncho sipadzakhala munthu wokuzindikilani mu kafukufukuyu.

Kodi chidzachitike ndi chiyani pambuyo pake?	
	Ndidzalemba ripoti lokhudzana ndi zokambirana zathu ndipo ndikhoza kuzakapo chithunzi chomwe mudzajambule. Dzina lanu silidzagwiritsidwa ntchito. Padzatha kudzakhala chionetselo cha zithunzi zimene zinajambulidwa ndi otengapo mbali onse a kafukufukuyu. Ngati izi zidzachitike mudzaitanidwa kuti mudzabwere kuti mudzathe kuona zithunzizo zosiyana-siyana pamenepo.
Kodi pali ziopsezo zili zonse?	
	Palibe ziopsezo zina zili zonse zoyembekezereka. Koma ngati mungakhale ndi nkhwawa kapena kukumana ndi vuto linai lilili onse pa nthawi ya kafukufukuyu kapena pambuyo pake mukhoza kundidziwitsa kuti ndikuthandizeni. Mukhozanso kuimba pa manambala awa: <ul style="list-style-type: none"> • Tithandizane National Child Helpline. Chonde imbani nambala: 116 • Teen Support Line. Chonde imbani nambala: 53535
Kodi pali phindu lina liri lonse potenga nawo mbali mu kafukufukuyu?	
	Ngakhale mukhoza kusangalatsidwa ndi kutenga mbali mu kafukufukuyu, palibe phindu leni leni logwirika. Kudzera m'mayankho omwe mudzapereke, mabuku ophunzitsira za kachilomboka adzapititsidwa patsogolo. Zakumwa zidzaperekedwa pa zokambirana za mu magulu ndipo mudzalandira 2,000 kwacha ya mayendedwe.
Kodi ndingapeze kuti zambiri zokhudzana ndi kafukufukuyu?	
	Ngati muli ndi mafunso ena ali onse okhudzana ndi kafukufukuyu chonde lumikizanani ndi ine: Nadine Ammon E-mail: n.ammon@lancaster.ac.uk Telephone: +265 992 273 433
	Zikomo chifukwa chowerenga chifomu ichi! 

Appendix 13. Participant Information Sheet for adolescents (17-19 years, English)



Participant Information Sheet

Title of Study: Perceptions and experiences of adolescents living with HIV in Malawi

My name is Nadine Ammon, I am a nurse and I am conducting this research as part of my PhD studies at Lancaster University, United Kingdom. I would like to ask you to participate in this study. Please read this information sheet as it is important that you understand what it means to participate in this study before you make a decision.

What is the study about?

In this study we want to learn about the experiences and perceptions of adolescents living with HIV in Malawi and how they imagine the virus. We will use the results of the study to improve the education information used in the clinics to help other young people.

Why have I been approached?

You have been chosen to participate because you are between 10 and 19 years old and living with HIV. We want to learn more about your experiences so that we can improve education materials used in our clinics and elsewhere.

Do I have to take part?

No. It's completely up to you to decide whether or not to take part.

You can stop taking part at any time, and you do not need to share information you don't want to. You can remove your consent for using the data until 4 weeks after the interviews and without giving a reason for this. After the 4 weeks it will not be possible to remove the contributions, but all data will be anonymised. Your decision will not have any effect on the care you receive.

What will I be asked to do if I take part?

If you decide to participate in the study, you would be asked to contact me for a personal meeting in which you will get more information about the study, and you will be able to ask questions. If you decide to participate, will be asked to sign an assent/consent form. For the study, you will come to the peer support group at [REDACTED] clinic, which you are already attending. This is where the study will take place. You will be asked to come on three days for two interviews and one group discussion which will each take about 1 hour; during the first interview a drawing session will be included. During the group discussion there will be three more participants and all members will be asked to answer and discuss questions. The

date and time of the interviews will be arranged with you, so that it does not disturb your schooling or working schedule. You will be interviewed by me and a [REDACTED] clinic staff member will help with translations.

Questions you will be asked are about your experiences living with the virus. With your permission the interviews will be audio recorded, so that I can remember what we discussed. If you would like to keep the drawing, you will receive it after I have made a scan of it.

Will my identity be known by others?

Everything you tell me in the interviews will be confidential.

The information collected for this study will be stored securely and only the researchers conducting this study will have access to this information:

- Audio recordings will be deleted once the project has been completed.
- The drawings will be kept securely in a locked cabinet for 10 years. Then they will be destroyed.
- The files on the computer will be encrypted (that is no-one other than the researcher will be able to access them) and the computer itself password protected.

The interviews will be typed and your personal information, such as your name will be removed so that nobody can identify you in this information. Direct quotations from your interviews may be used in the reports or publications from the study, so your name will not be attached to them. All your personal data will be confidential and will be kept separately from your interview responses. There are some limits to confidentiality: if what is said in the interview makes me think that you, or someone else, is at significant risk of harm, I will have to speak to a member of staff about this, but I will tell you if this is the case.

What will happen to the results?

The results will be summarised and reported to Lancaster University. They may be also presented on a conference. Your name will not appear in any report, publication or presentation made. There might be an exhibition of the drawings that were produced by all participants. If this takes place you will receive an invitation to come and see the different drawings there.

Are there any risks?

There are no expected risks with participating in this study. However, if you experience any worry or distress during or after participation you are encouraged to inform the researcher, who is an experienced nurse, so that immediate counselling can be arranged. You can also contact one of the telephone numbers provided at the end of this sheet.

Are there any benefits to taking part?

Although you may find participating interesting, there are no direct benefits in taking part. Through the information you will share, HIV education material might be reviewed and improved. Refreshments will be provided during the group discussions and you will receive 2.000MK as transport reimbursement.

Who has reviewed the project?

This study has been reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University, UK and the National Commission for Science and Technology in Malawi.

Where can I get further information about the study if I need it?

If you have any questions about the study, please contact the main researcher:

Nadine Ammon

E-mail: n.ammon@lancaster.ac.uk

Telephone: +265 992 273 433

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Professor Fiona Lobban

Director of Research, Division of Health Research at Lancaster University

Email: f.lobban@lancaster.ac.uk

Telephone: +44 1524 593752

If you wish to speak to someone outside of the Doctorate Programme, you may also contact:

Dr Laura Machin

Chair of FHM REC, Faculty of Health and Medicine, Lancaster University

LA1 4YG, Lancaster

Tel: +44 1524 594973

Email: l.machin@lancaster.ac.uk

In case you have questions relating to your rights or you want to report violation of your rights, you can contact:

Secretariat, National Committee on Research in the Social Sciences and Humanities,

National Commission for Science and Technology

Lingadzi House, City Centre

P/Bag B303, Capital City

Lilongwe 3

Malawi.

Tel.: +265 771 550/774 869

E-mail: ncrsh@ncst.mw

Thank you for taking the time to read this information sheet.

If you need to contact someone after the interview you can call:

- Tithandizane National Child Helpline; *toll-free number: Please dial: 116*
- Teen Support Line; anonymous toll-free number: Please dial: 53535
- Designated trained counsellor at [REDACTED] clinic

Appendix 14. Participant Information Sheet for adolescents (17-19 years, Chichewa)



Chifomu cha otenga nawo mbali cha achinyamata

(a zaka zapakati pa 17 mpaka 19)

Mutu wa kafukufuku: Malingaliro ndi m'mene akukhalira achinyamata amene ali ndi kachilombo ka HIV ku Malawi

Dzina langa ndine Nadine Ammon. Ndine namwino ndipo ndikupanga kafukufukuyu monga mbali imodzi ya maphunziro anga a PhD ku sukulu ya ukachenjede ya Lancaster ku England. Ndikukupemphani kuti mutenge nawo mbali mu kafukufukuyu. Chonde werengani chifomu ichi chifukwa izi ndi chofunikira kwambiri kuti mumvetsetse musanapange chiganizo chotenga nawo mbali.

Kodi kafukufukuyu ndi okhudzana ndi chiyani?

Mu kafukufukuyu tikufuna tidziwe m'mene achinyamata omwe ali ndi kachilombo akukhalira komanso malingaliro awo ku Malawi ndipo m'mene akuganizira za maonekedwe a kachilomboka. Tidzagwiritsa ntchito zotsatira za kafukufukuyu kupititsa patsogolo mabuku amene amagwiritsidwa ntchito mu zipatala kuti zithandize achinyamata ena.

Kodi ndasankhidwa chifukwa chiyani?

Mwasankhidwa kuti mutenge nawo mbali mu kafukufukuyu chifukwa muli ndi zaka zakubadwa za pakati pa 10 ndi 19 ndipo mukukhala ndi kachilombo ka HIV.

Tikufuna kudziwa za m'mene mukukhalira ndi kachilombo ka HIV ndi malingaliro anu komanso ndi m'mene mumaganizira za maonekedwe a kachilomboka.

Kodi ndikuyenera kutengapo mbali?

Ayi. Zikutengera inuyo kwathunthu kupanga chiganizo chotengapo mbali kapena ayi.

Mukhoza kusiya kutengapo mbali pa nthawi ina ili yonse ndipo simukuyenera kufotokoza zinthu zimene simukufuna. Mukhoza kutiletsa kuti tisagwiritse ntchito mayankho anu masabata anayi asanadutse posapereka chifukwa chili chonse koma akadutsa ndiye sizingathekenso chifukwa pa nthawiyi zidzakhala zitalembedwa.

Chisankho chanu sichidzakhudza chisamaliro chimene mukulandira ku chipatala.

Kodi ndidzafunsidwa kuti nditani ndikasankha kutenga nawo mbali mu kafukufukuyu?

Mukapanga chiganizo kutenga nawo mbali mu kafukufukuyu, mudzafunsidwa kuti mulumikizane ndi ine kuti tiyankhulane kuti mudzathe kumvetsetsa zambiri zokhudzana ndi kafukufukuyu ndipo mudzathanso kufunsa mafunso. Ngati mwapanga chiganizo kutengapo mbali kusayina chifomu cha chilolezo. Kafukufukuyu adzapangidwira ku chipatala cha █████ komwe mumapita ndikale choncho mudzayenera kubwera ku chipatalachi. Uku ndi kumene kafukufukuyu adzachitikire. Mudzapemphedwa kuti mudzabwere masiku atatu kuti mudzafunsidwe mafunso kawiri panokha ndipo kachitatu pa gulu, izi zizidzatenga ola limodzi limodzi; pamafunso oyamba mudzafunsidwa kuti mujambule. Pa kukumana kwathu kwa m'magulu padzakhala otenga nawo mbali apadera atatu ndipo mudzapemphedwa kukambirana mafunso. Nthawi ndi tsiku la kafukufukuyu zidzakhazikitsidwa ndi inu kuti zisasokoneze zochita zanu za tsiku ndi tsiku. Mudzafunsidwa mafunso ndi ine ndi m'modzi mwa anthu ogwira ntchito ku chipatala cha █████ amene adzathandizire kutanthauzira. Mafunso omwe mudzafunsidwe adzakhala okhudzana m'mene mukukhalira ndi zomwe mukudutsamo ndi kachilomboka. Ndi chilolezo chanu mafunsowa adzajambulidwa ndi makina ojambulira mawu kuti ndikathe kukumbukira zomwe tinakambirana. Ngati mungafune kusunga zithunzi zojambula mudzalandira ndikaziunika ndi kuziona.

Kodi ndidzazindikirika ndi ena?

Chili chonse chimene mudzandifotokozere chidzakhala cha chinsinsi. Mfundo zonse zitoleledwe mu kafukufukuyu zidasungidwa motetezedwa ndipo wofufuza okhawa amene akupanga kafukufukuyu ndi amene adzatha kuzifikira:

- Zimene zidzajambulidwe zidzafufutidwa kafukufukuyui akadzangotha.
- Zinthuzi zidasungidwa motetezedwa mu bokosi lotsekedwa ndi maloko kwa zaka 10. Kenako zidzaonongedwa.
- Mafailo a pa komputa adzakhala otetezedwa ndi nambala ya chinsinsi (kotero kuti palibe amene angawafikire kupatula ofufuza okhoa basi).

Zokambirana zathuzi zidzatayipidwa koma dzina lanu lidzachotsedwa choncho sipadzakhala munthu wokuzindikilani mu kafukufukuyu. Zina mwa mayankho anu zidzatha kugwiritsidwa ntchito mu maripoti kapena timabuku kuchokera mu kafukufukuyu koma dzina lanu lidzachotsedwamo. Dzina lanu ndi zonse zokhudza inu zidzakhala za chinsinsi ndipo zidasungidwa molekana ndi mayankho anu mu kafukufukuyu. Komabe pali malire pa kusunga chinsinsi, ngati zomwe zanenedwa mu kafukufuku zandiganizitsa kuti inu kapena wina wake ali pa chiopsezo, ndidzayenera kuphwanya malamulo osunga chinsinsi ndi kulankhula ndi ogwira ntchito ku chipatala cha █████ za chimenechi. Ndidzakuuzani izi zikadzakhala motere.

Chidzachitike ndi chiyani ku zotsatira za kafukufukuyu?

Zotsatirazi zidzaunikidwa ndi kutumizidwa ku sukulu ya ukachenjede ya Lancaster ku England. Zidzakhosanso kugwiritsidwa ntchito pa msokhano waukulu. Dzina lanu silidzalembedwa mu ripoti lina lili lonse, kapena mu timabuku kapenanso kutchulidwa pa misonkhano. Padzatha kudzakhala chionetselo cha zithunzi zimene

zinajambulidwa ndi otengapo mbali onse a kafukufukuyu. Izi zikadzachitika mudzayitanidwa kuti mudzabwere kudzaona zithunzi zosiyana-siyana kumeneko.

Kodi pali ziopsezo zili zonse?

Palibe ziopsezo zoyembekezereka potenga nawo mbali mu kafukufukuyu.

Komabe ngati mkati mwa kafukufukuyu kapena kumapeto kwake mukuchita mantha kapena kukhala ndi nkhwawa mukupemphedwa kuti mudzauze wofufuza amene ndi namwino wodziwa bwino ntchito yake kuti mupatsidwe uphungu woyenera mwachangu. Mukhozanso kuyimba lanya pa manambala ali ku mapeto kwa chikalatachi.

Kodi pali phindu lina liri lonse potenga nawo mbali mu kafukufukuyu?

Ngakhale mukhoza kusangalatsidwa ndi kutenga mbali mu kafukufukuyu, palibe phindu leni leni logwirika. Kudzera m'mayankho omwe mudzapereke, mabuku ophunzitsira za kachilombo ka HIV adzaunikidwanso ndi kupititsidwa patsogolo. Zakumwa zidzaperekedwa pa zokambirana za mu magulu ndipo mudzalandira 2,000 kwacha ya mayendedwe.

Kodi ndi ndani amene anaunikanso projekiti?

Kafukufukuyu waunikidwa ndi kuvomerezedwa ndi Nthambi ya za Umoyo ndi kafukufuku wa Mankhwala ku sukulu ya ukachenjede ya Lancaster ku England ndiponso ndi komishoni ya za Sayansi ndi Tekinoloje ku Malawi.

Kodi ndingapeze kuti uthenga wokhudzana ndi kafukufukuyu, ndikaufuna?

Ngati muli ndi mafunso ena ali onse okhudzana ndi kafukufukuyu chonde lumikizanani ndi wofufuza wankulu:

Nadine Ammon

E-mail: n.ammon@lancaster.ac.uk

Telephone: +265 992 273 433

Madandaulo

Ngati pali dandaulo liri lonse lokhudzana ndi kafukufuku ameneyu ndipo ngati simukufuna kuyankhula ndi wofufuza lumikizanani ndi:

Professor Fiona Lobban

Director of Research, Division of Health Research at Lancaster University

Email: f.lobban@lancaster.ac.uk

Telephone: +44 1524 593752

Ngati mukufuna kulankhula ndi wina wake amene sakupanga nawo kafukufuku mutha kulumikizana ndi:

Dr Laura Machin

Chair of FHM REC, Faculty of Health and Medicine, Lancaster University

LA1 4YG, Lancaster

Tel: +44 1524 594973

Email: l.machin@lancaster.ac.uk

Ngati muli ndi mafunso ena ali onse okhudzana ndi ufulu wanu oro mukufuna kuziwise kuphwanyiridwa ufulu wanu chonde lumikizani:

Secretariat, National Committee on Research in the Social Sciences and Humanities,

National Commission for Science and Technology

Lingadzi House, City Centre

P/Bag B303, Capital City

Lilongwe 3, Malawi.

Tel.: +265 771 550/774 869

E-mail: ncrsh@ncst.mw

Zikomo kwambiri potenga nthawi kuti muwerenge chifomu ichi.

Mukafuna kulankhula ndi wina wake mukatha kufunsidwa mafunsowa, mutha kuyimbira:

- Tithandizane National Child Helpline. Chonde imbani nambala: 116
- Teen Support Line. Chonde imbani nambala: 53535
- Wopereka ophungu wotumizidwa ku chipatala cha [REDACTED]

Appendix 15. Participant Information Sheet for parents and caregivers (English)



Participant Information Sheet

Title of Study: Perceptions and experiences of adolescents living with HIV in Malawi

My name is Nadine Ammon, I am a nurse, and I am conducting this research as part of my PhD studies at Lancaster University, Lancaster, United Kingdom. I would like to ask your child to participate in this study. Please read this information sheet as it is important that you and your child understand what it means to participate in this study before you make a decision together.

What is the study about?

In this study we want to learn about the experiences and perceptions of adolescents living with HIV in Malawi and how they imagine the virus. We will use the results of the study to improve the education information used in the clinics to help other young people.

Why have I been approached?

Your child has been approached because they are aged 10 to 19 years old and living with HIV. We want to learn more about their experiences so that we can improve education materials used in our clinics and elsewhere.

Does my child have to take part?

No. It's completely up to you and your child to decide whether or not to take part.

You and your child can stop taking part at any time, and you do not need to share information you don't want to. You can remove your consent for using the data until 4 weeks after the interviews and without giving a reason for this. After the 4 weeks it will not be possible to remove the contributions, but all data will be anonymised. Your decision will not have any effect on the care you receive.

What will I and my child be asked to do if my child takes part?

If you and your child decide to participate in the study, you would be asked to contact me for a personal meeting in which you will get more information about the study, and you and your child will be able to ask questions. If you and your child decide to participate, both of you will be asked to sign a consent form.

For the study, your child will come to the peer support group at [REDACTED] clinic, which your child is already attending. This is where the study will take place. Your child will be asked to come on three days for two interviews and 1 group discussion which will each take about 1 hour; during the first interview a drawing session will be included.

During the group discussion there will be three more participants and all members will be asked to answer and discuss questions. The date and time of the interviews will be arranged with you and your child, so that it does not disturb your child's schooling or working schedule.

Your child will be interviewed by me and a [REDACTED] clinic staff member will help with translations.

Questions your child will be asked are about his/her experiences living with the virus. With your permission the interviews will be audio recorded, so that I can remember what we discussed. If your child would like to keep the drawing, the researcher will do so after she has made a scan of it.

Will my child's identity be known by others?

Everything your child tells me in the interviews will be confidential.

The information collected for this study will be stored securely and only the researchers conducting this study will have access to this data:

- Audio recordings will be destroyed and/or deleted once the project has been submitted for publication.
- The drawings will be kept in a locked cabinet.
- The files on the computer will be encrypted (that is no-one other than the researcher will be able to access them) and the computer itself password protected.
- At the end of the study, the drawings will be destroyed.

The typed version of the interview will be made anonymous by removing any identifying information including your child's name. Anonymised direct quotations from the interview may be used in the reports or publications from the study, so your child's name will not be attached to them. All reasonable steps will be taken to protect the anonymity of the participants involved in this project. All personal data of your child will be confidential and will be kept separately from the interview responses. There are some limits to confidentiality: if what is said in the interview makes me think that your child, or someone else, is at significant risk of harm, I will have to speak to a member of staff about this, but I will tell you and your child if this is the case.

What will happen to the results?

The results will be summarised and reported to Lancaster University and may be submitted for publication in an academic or professional journal. They may be also presented on a conference. Your child's name will not appear in any report, publication or presentation made. There might be an exhibition of the drawings that were produced by all participants. If this takes place you and your child will receive an invitation to come and see the different drawings there.

Are there any risks?

There are no expected risks with participating in this study. However, if your child experiences any worry or distress during or after participation you and your child are encouraged to inform the researcher, who is an experienced nurse, so that immediate counselling can be arranged. You can also contact one of the telephone numbers provided at the end of this sheet.

Are there any benefits to taking part?

Although your child may find participating interesting, there are no direct benefits in taking part. Through the information your child will share, HIV education material might be reviewed and improved. Refreshments will be provided during the group discussions. Your child will receive 2.000MK as transport reimbursement for each meeting.

Who has reviewed the project?

This study has been reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University, UK and the National Commission for Science and Technology in Malawi.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the main researcher:

Nadine Ammon

E-mail: n.ammon@lancaster.ac.uk

Telephone: +265 992 273 433

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Professor Fiona Lobban

Director of Research, Division of Health Research at Lancaster University

Email: f.lobban@lancaster.ac.uk

Telephone: +44 1524 593752

If you wish to speak to someone outside of the Doctorate Programme, you may also contact:

Dr Laura Machin

Chair of FHM REC, Faculty of Health and Medicine, Lancaster University

LA1 4YG, Lancaster

Tel: +44 1524 594973

Email: l.machin@lancaster.ac.uk

In case you have questions relating to your rights or you want to report violation of your rights, you can contact:

Secretariat, National Committee on Research in the Social Sciences and Humanities,
National Commission for Science and Technology

Lingadzi House, City Centre

P/Bag B303, Capital City

Lilongwe 3

Malawi.

Tel.: +265 771 550/774 869

E-mail: ncrsh@ncst.mw

Thank you for taking the time to read this information sheet.

If you or your child need to contact someone after the interview you can call:

- Tithandizane National Child Helpline. *Toll-free number: Please dial 116*
- Teen Support Line. *Anonymous toll-free number: Please dial 53535*
- Designated trained counsellor at [REDACTED] clinic

Appendix 16. Participant Information Sheet for parents and caregivers (Chichewa)



Chifomu cha otenga nawo mbali mu kafukufuku cha makolo ndi oyang'anira odwala

Mutu wa kafukufuku: Malingaliro ndi m'mene akukhalira achinyamata amene ali ndi kachilombo ka HIV ku Malawi

Dzina langa ndine Nadine Ammon. Ndine namwino ndipo ndikupanga kafukufukuyu ngati mbali imodzi ya maphunziro anga a PHD ku sukulu ya ukachenjede ya Lancaster ku England. Ndikupempha kuti mwana wanu atenge nawo mbali mu kafukufukuyu. Chonde werengani chifomu ichi chifukwa ndi chofunikira kwambiri kuti inu ndi mwana wanu muthe kumvetsetsa za kafukufukuyu musanapange chiganizo chotenga nawo mbali limodzi.

Kodi kafukufukuyu ndi okhudzana ndi chiyani?

Mu kafukufukuyu tikufuna tidziwe m'mene achinyamata omwe ali ndi kachilombo akukhalira komanso malingaliro awo ku Malawi ndipo m'mene akuganizira za maonekedwe a kachilomboka. Tidzagwiritsa ntchito zotsatira za kafukufukuyu kupititsa patsogolo mabuku amene amagwiritsidwa ntchito mu zipatala kuti zithandize achinyamata ena.

Kodi ndasankhidwa chifukwa chiyani?

Mwasankhidwa kuti mutenge nawo mbali mu kafukufukuyu chifukwa muli ndi zaka zakubadwa za pakati pa 10 ndi 19 ndipo mukukhala ndi kachilombo ka HIV. Tikufuna kudziwa za m'mene mukukhalira ndi kachilombo ka HIV ndi malingaliro anu komanso ndi m'mene mumaganizira za maonekedwe a kachilomboka.

Kodi mwana wanga akuyenera kutengapo mbali?

Ayi. Zikutengera inuyo kwathunthu ndi mwana wanu kupanga chiganizo chotengapo mbali kapena ayi. Inu ndi mwana wanu mukhoza kusiya kutengapo mbali pa kafukufukuyu pa nthawi ina ili yonse, ndipo simukuyenera kufotokoza zinthu zimene simukufuna. Mukhoza kutiletsa kuti tisagwiritse ntchito mayankho anu masabata anayi asanadutse posapereka chifukwa chili chonse koma akadutsa ndiye sizingathekenso chifukwa pa nthawiyi zidzakhala zitalembedwa. Chisankho chanu sichidzakhudza chisamaliro chimene mukulandira ku chipatala.

Kodi mwana wanga ndi ine tidzafunsidwa kupanga chiyani ngati mwana wanga angatengepo mbali mu kafukufukuyu?

Ngati inu ndi mwana wanu mwapanga chiganizo chotenga nawo mbali mu kafukufukuyu, mudzapemphedwa kuti mulumikizane ndi ine kuti tiyankhulane kuti mudzathe kumvetsetsa zambiri zokhudzana ndi kafukufukuyu ndipo mudzathanso kufunsa mafunso. Ngati nonse inu ndi mwana wanu mwapanga chiganizo chotenga nawo mbali mu kafukufukuyu, nonse mudzafunsidwa kusayina chifomu cha chilolezo. Kafukufukuyu adzapangidwira ku chipatala cha [REDACTED] komwe mumapita ndikale choncho mudzayenera kubwera ku chipatalachi. Uku ndi kumene kafukufukuyu adzachitikire. Mwana wanu adzapemphedwa kubwera kwa masiku atatu kuti adzafunsidwe mafunso kawiri zokambirana za pagulu kamodzi mafunsowa ndi zokambirana za pagulu zidzidzatenga ola limodzi limodzi; pamafunso oyamba mwana wanu adzafunsidwa kuti ajambule. Pa kukumana kwathu kwa m'magulu padzakhala otenga nawo mbali apadera atatu ndipo mudzapemphedwa kukambirana mafunso. Mwana wanu adzafunsidwa mafunso ndi ine ndi wogwira ntchito ku chipatala cha [REDACTED] adzathandiza kumasulira. Mafunso amene mwana wanu adzafunsidwe ndi okhudzana ndi m'mene akukhalira ndi kachilombo ka HIV. Ndi chilolezo chanu mafunsowa adzajambulidwa ndi makina ojambulira mawu kuti ndikathe kukumbukira zomwe tinakambirana. Ngati mwana wanu adzafuna kusunga chithunzi adzapatsidwa wofufuza akadzachijambula. Ngati mungafune kusunga zithunzi zojambula mudzalandira ndikaziunika ndi kuziona.

Kodi mwana wanga adzazindikirika ndi ena?

Chili chonse chimene mwana wanu adzandifotokozere chidzakhala cha chinsinsi.

Mfundo zonse zitoleledwe mu kafukufukuyu zidasungidwa motetezedwa ndipo wofufuza okhawa amene akupanga kafukufukuyu ndi amene adzatha kuzifikira:

- Mau ojambulidwa pa makina ojambulira mau adzafufutidwa mfundo za kafukufuku zikangotumizidwa kukatsindikidwa.
- Zinthuzi zidasungidwa motetezedwa mu bokosi lokhomedwa
- Mafailo a pa komputa adzakhala otetezedwa (kotero kuti palibe amene angawafikire kupatula ofufuza okha basi.
- Zinthunzizi zidasungidwa motetezedwa mu bokosi lokhomedwa ndi maloko kwa zaka 10. Kenako zidzaonongedwa.

Mafunso ndi mayankho otayipidwa sizidzakhala ndi dzina la mwana wanu.

Mayankho ena ndi ena ochokera mumayankho a mwana wanu adzagwiritsidwa ntchito mu malipoti kapena mumabuku komabe sadzakhala ndi dzina la mwana wanu. Njira zomveka bwino zidzagwiritsidwa ntchito kuonetsetsa kuti ali yense amene anatenga nawo mbali mu kafukufukuyu atetezedwe. Dzina la mwana wanu sidzalembedwa paliponse kapena kutchulidwa koma mayankho okha a mwana wanu ndi amene adzagwiritsidwa ntchito. Komabe pali malire pa kusunga chinsinsi, ngati zomwe zanenedwa mu kafukufuku zandiganizitsa kuti mwana wanu kapena wina wake ali pa chiopsezo, ndidzayenera kuphwanya malamulo osunga chinsinsi ndi kulankhula ndi ogwira ntchito ku chipatala cha [REDACTED] za chimenechi. Ndidzakuuzani inu ndi mwana wanu izi zikadzakhala motere.

Chidzachitike ndi chiyani ku zotsatira za kafukufukuyu?

Zotsatira zidzalembedwanso mwachidule ndi kuperekedwa ku sukulu ya ukachenjede ya Lancaster ku England kuti zikhazikitsidwe mu mabuku ophunzitsira ndi aukadaulo. Zidzakhozanso kugwiritsidwa ntchito pa msokhano waukulu. Dzina la mwana wanu silidzalembedwa mu ripoti lina lili lonse, kapena timabuku kapenanso kutchulidwa pa misonkhano. Padzatha kudzakhala chionetselo cha zithunzi zimene zinajambulidwa ndi otengapo mbali onse a kafukufukuyu. Izi zikadzachitika, inu ndi mwana wanu mudzayitanidwa kuti mudzabwere kudzaona zithunzi zosiyana-siyana kumeneko.

Kodi pali ziopsezo zina zili zonse?

Palibe ziopsezo zoyembekezereka potenga nawo mbali mu kafukufukuyu.

Komabe ngati mwana wanu angakhale ndi mantha kapena kukhala ndi nkhwana chifukwa cha kafukufukuyu mkati mwa kafukufuku kapena kumapeto kwake, mwana wanu akulimbikitsidwa kuti auze wofufuza amene ndi namwino wodziwa bwino ntchito yake kuti apatsidwe uphungu woyenera mwachangu. Mukhozanso kuyimba lanya pa manambala ali ku mapeto kwa chikalatachi.

Kodi pali phindu lina liri lonse kutenga nawo mbali mu kafukufukuyu?

Ngakhale mwana wanu atha kusangalatsidwa ndi kafukufukuyu, palibe phindu leni leni logwilika potengapo mbali mu kafukufukuyu. Kudzera m'mayankho a mwana wanu ndi zimene adzakambirane m'gulu zidzathandiza kuunikanso ndi kupiititsa patsogolo mauthenga okhudzana ndi kachilombo ka HIV. Zakumwa zidzaperekedwa mkati mwazokambirana za pagulu, ndipo mwana wanu adzalandira 2,000 kwacha ya mayendedwe pa kukumana kuli konse.

Kodi ndi ndani amene anaunikanso projekiti?

Kafukufukuyu waunikidwa ndi kuvomeredwa ndi Nthambi ya za Umoyo ndi kafukufuku wa Mankhwala ku sukulu ya ukachenjede ya Lancaster ku England ndiponso ndi komishoni ya za Sayansi ndi Tekinoloje ku Malawi.

Kodi ndingapeze kuti uthenga wokhudzana ndi kafukufukuyu, ndikaufuna?

Ngati muli ndi mafunso ena ali onse okhudzana ndi kafukufukuyu chonde lumikizanani ndi wofufuza wankulu:

Nadine Ammon

E-mail: n.ammon@lancaster.ac.uk

Telephone: +265 992 273 433

Madandaulo

Ngati pali dandaulo liri lonse lokhudzana ndi kafukufuku ameneyu ndipo ngati simukufuna kuyankhula ndi wofufuza lumikizanani ndi:

Professor Fiona Lobban

Director of Research, Division of Health Research at Lancaster University

Email: f.lobban@lancaster.ac.uk

Telephone: +44 1524 593752

Ngati mukufuna kulankhula ndi wina wake amene sakupanga nawo kafukufuku mutha kulumikizana ndi:

Dr Laura Machin

Chair of FHM REC, Faculty of Health and Medicine, Lancaster University

LA1 4YG, Lancaster

Tel: +44 1524 594973

Email: l.machin@lancaster.ac.uk

Ngati muli ndi mafunso ena ali onse okhudzana ndi ufulu wanu oro mukufuna kuziwise kuphwanyiridwa ufulu wanu chonde lumikizanani:

Secretariat, National Committee on Research in the Social Sciences and Humanities,

National Commission for Science and Technology

Lingadzi House, City Centre

P/Bag B303, Capital City

Lilongwe 3

Malawi.

Tel.: +265 771 550/774 869

E-mail: ncrsh@ncst.mw

Zikomo kwambiri potenga nthawi kuti muwerenge chifomu ichi.

Mukafuna kulankhula ndi wina wake mukatha kufunsiidwa mafunsowa, mutha kuyimbira:

- Tithandizane National Child Helpline. Chonde imbani nambala: 116
- Teen Support Line. Chonde imbani nambala: 53535
- Wopereka ophungu wotumizidwa ku chipatala cha [REDACTED]

Participant Information Sheet

Title of Study: Perceptions and experiences of adolescents living with HIV in Malawi

My name is Nadine Ammon, I am a nurse, and I am conducting this research as part of my PhD studies at Lancaster University, Lancaster, United Kingdom. Please read this information sheet as it is important that you understand what it means to participate in this study before you make a decision.

What is the study about?

The purpose of this study is to learn about the experiences and perceptions adolescents living with HIV in Malawi. The study aims to understand how the adolescents imagine the HIV-virus and what impact this has on their lives.

Why have I been approached?

You have been approached because the study requires information from people who are working with adolescents living with HIV and who are able to share their experiences. Furthermore, visual data, produced by HIV-positive adolescents need interpretation of service providers who are experienced in the work with adolescents living with HIV. This information will help when reviewing educational material used at health facilities. Through your participation in the study, the educational material, which is currently used, could be improved.

Do I have to take part?

No. It's completely up to you to decide whether or not you take part. You can withdraw your consent at any time, and you do not need to share information you don't want. There will be no negative consequence for not participating or withdrawing at a later stage.

What will I be asked to do if I take part?

If you decide you would like to take part, you would be asked to come to the [REDACTED] clinic. This is where the study will take place. You will be asked to come on one day for one focus group discussion which will take about 1 hour.

Will my data be identifiable?

The data collected for this study will be stored securely and only the researchers conducting this study will have access to this data:

- Audio recordings will be destroyed and/or deleted once the project has been submitted for publication
- Hard copies of questionnaires and consent forms will be kept in a locked cabinet.
- The files on the computer will be encrypted (that is no-one other than the researcher will be able to access them) and the computer itself password protected.
- At the end of the study, hard copies of questionnaires will be kept securely in a locked cabinet for ten years and afterwards they will be destroyed.

The typed version of your interview will be made anonymous by removing any identifying information including your name. Anonymised direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them. All reasonable steps will be taken to protect the anonymity of the participants involved in this project. All your personal data will be confidential and will be kept separately from your interview responses. There are some limits to confidentiality: if what is said in the interview makes me think that you, or someone else, is at significant risk of harm, I will have to break confidentiality and speak to a member of staff about this. If possible, I will tell you if I have to do this.

What will happen to the results?

The results will be summarised and reported in a thesis and may be submitted for publication in an academic or professional journal. They may be also presented on a conference. Your name will not appear in any publication or presentation made. There might be an exhibition of the drawings that were produced by the adolescent participants. If this takes place you will receive an invitation to come and see the different drawings there.

Are there any risks?

There are no risks anticipated with participating in this study. However, if you experience any distress following participation you are encouraged to inform the researcher and contact the resources provided at the end of this sheet.

Are there any benefits to taking part?

Although you may find participating interesting, there are no direct benefits in taking part. Through the information you will share HIV education material might be reviewed and improved. Refreshments will be provided during the focus group discussion. You will receive 2.000MK for your transport and time.

Who has reviewed the project?

This study has been reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University, UK and the College of Medicine Research and Ethics Committee in Malawi.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the main researcher:

Nadine Ammon

E-mail: n.ammon@lancaster.ac.uk

Telephone: +265 992 273 433

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Professor Fiona Lobban

Director of Research, Division of Health Research at Lancaster University

Email: f.lobban@lancaster.ac.uk

Telephone: +44 1524 593752

If you wish to speak to someone outside of the Doctorate Programme, you may also contact:

Dr Laura Machin

Chair of FHM REC, Faculty of Health and Medicine, Lancaster University

LA1 4YG, Lancaster

Tel: +44 1524 594973

Email: l.machin@lancaster.ac.uk

In case you have questions relating to your rights or you want to report violation of your rights, you can contact:

Secretariat, National Committee on Research in the Social Sciences and Humanities,
National Commission for Science and Technology

Lingadzi House, City Centre

P/Bag B303, Capital City, Lilongwe 3, Malawi.

Tel.: +265 771 550/774 869

E-mail: ncrsh@ncst.mw

Thank you for taking the time to read this information sheet.

Resource list: Designated trained counsellor at [REDACTED] clinic

Appendix 18. Assent form for adolescents living with HIV (10-17 years, English)



Assent form for adolescents (10-17 years)

Project Title: Perceptions and experiences of adolescents living with HIV in Malawi

Name of Researcher: Nadine Ammon

Email: n.ammon@lancaster.ac.uk



Please tick the boxes for each statement

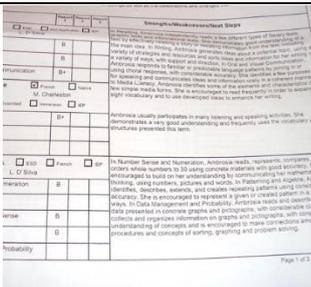
	<p>I have read / heard and understood the information sheet.</p> <p>YES <input type="checkbox"/></p>
	<p>I have been able to ask questions</p> <p>YES <input type="checkbox"/> NO <input type="checkbox"/></p>
	<p>I know I can stop at any time and nobody will mind.</p> <p>YES <input type="checkbox"/> NO <input type="checkbox"/></p>



I agree that the researcher can record our discussions or interviews.

YES

NO



The researcher will use my words from our conversation and drawing when writing her report but will not use my name or personal details.

YES

NO



I know the researchers won't tell anyone what I have said about the research but if I tell them I am going to hurt myself or anyone else then they will talk with a staff member at [REDACTED] Clinic.

YES

NO



I want to take part in this research.

YES

NO



I know I will still receive the usual care and support at [REDACTED] Clinic even if I do not take part in the research.

YES

NO

Name of participant	Date	Signature or thumb print
Name of researcher	Date	Signature

One copy of this form will be given to the participant and the original kept in the files of the researcher at Lancaster University.

Appendix 19. Assent form for adolescents living with HIV (10-17 years, Chichewa)



Chifomu cha chilolezo cha achinyamata
(a zaka zapakati pa 10 mpaka 17)

Mutu wa Projekiti: Malingaliro ndi m'mene akukhalira achinyamata amene ali ndi kachilombo ka HIV ku Malawi

Dzina la Wofufuza: Nadine Ammon

Email: n.ammon@lancaster.ac.uk



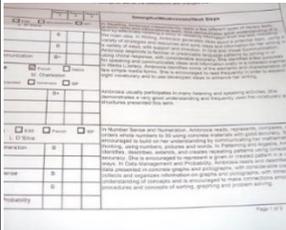
Chonde chongani mu kabokosi la funso lina liri lonse

	<p>Ndawerenga/ ndamva ndipo ndamvetsetsa zokhudzana ndi fomu iyi.</p> <p style="text-align: center;">INDE <input type="checkbox"/> AYI <input type="checkbox"/></p>
	<p>Ndakwaniritsa kufuna mafunso.</p> <p style="text-align: center;">INDE <input type="checkbox"/> AYI <input type="checkbox"/></p>
	<p>Ndikudziwa kuti ndikhoza kusiya nthawi ina ili yonse ndipo palibe amene zimudandaulitse.</p> <p style="text-align: center;">INDE <input type="checkbox"/> AYI <input type="checkbox"/></p>



Ndikuvomerezana ndi wofufuza kuti akhoza kujambula mawu pa zokambirana ndi mafunso athu.

INDE AYI



Wofufuza adzagwiritsa ntchito mayankho anga kuchokera mu zokambirana ndi chithunzi changa polemba ma ripoti opanda dzina langa.

INDE AYI



Ndikudziwa kuti wofufuzasadzauza aliyense zokhudzana ndi zomwe ndafotokoza za kafukufuku koma ndikawafotokozero ndidzamva kupweteka ndekha kapena ena choncho adzayankhulana ndi ma membala a chipatala cha ██████.

INDE AYI



Ndikufuna kutenga nawo mbali mu kafukufukuyu.

INDE AYI



Ndikudziwa kuti ndipitiriza kulandira thandizo ndi chisamaliro ku chipatala cha [REDACTED] ngakhale ndisatenge nawo mbali mu kafukufukuyu.

INDE AYI

Dzina la otenga mbali mu kafukufuku	Tsiku	Sayinani kapena kudinda ndi chala
Dzina la wofufuza	Tsiku	Sayinani

Chifomu chimodzi chidzaperekedwa kwa otenga nawo mbali mu kafukufuku ndipo china chidzasungidwa ndi wofufuza ku sukulu ya ukachenjede ya Lancaster ku England.

Appendix 20. Consent Form for adolescents (18-19 years, English)



Consent form for adolescents (18-19 years)

Project Title: Perceptions and experiences of adolescents living with HIV in Malawi

Name of Researcher: Nadine Ammon

Email: n.ammon@lancaster.ac.uk



Please tick the boxes for each statement

	<p>I have read / heard and understood the information sheet.</p> <p>YES <input type="checkbox"/></p>
	<p>I have been able to ask questions</p> <p>YES <input type="checkbox"/> NO <input type="checkbox"/></p>



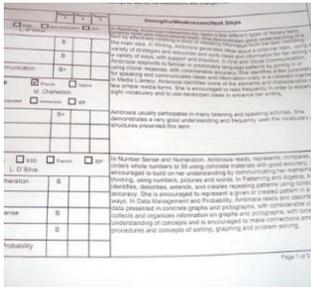
I know I can stop at any time and nobody will mind.

YES NO



I agree that the researcher can record our discussions or interviews.

YES NO



The researcher will use my words from our conversation and drawing when writing her report but will not use my name or personal details.

YES NO



I know the researchers won't tell anyone what I have said about the research but if I tell them I am going to hurt myself or anyone else then they will talk with a staff member at [REDACTED] Clinic.

YES NO

	<p>I want to take part in this research.</p> <p>YES <input type="checkbox"/> NO <input type="checkbox"/></p>
	<p>I know I will still receive the usual care and support at [REDACTED] Clinic even if I do not take part in the research.</p> <p>YES <input type="checkbox"/> NO <input type="checkbox"/></p>

Name of participant	Date	Signature or thumb print
Name of researcher	Date	Signature

One copy of this form will be given to the participant and the original kept in the files of the researcher at Lancaster University.

Appendix 21. Consent Form for adolescents (18-19 years, Chichewa)



Chifomu cha chilolezo cha achinyamata
(a zaka zapakati pa 18 mpaka 19)

Mutu wa Projekiti: Malingaliro ndi m'mene akukhalira achinyamata amene ali ndi kachilombo ka HIV ku Malawi

Dzina la Wofufuza: Nadine Ammon

Email: n.ammon@lancaster.ac.uk



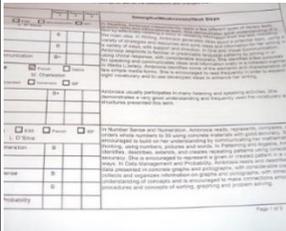
Chonde chongani mu kabokosi la funso lina liri lonse

	<p>Ndawerenga/ ndamva ndipo ndamvetsetsa zokhudzana ndi fomu iyi.</p> <p style="text-align: center;">INDE <input type="checkbox"/> AYI <input type="checkbox"/></p>
	<p>Ndakwaniritsa kufuna mafunso.</p> <p style="text-align: center;">INDE <input type="checkbox"/> AYI <input type="checkbox"/></p>
	<p>Ndikudziwa kuti ndikhoza kusiya nthawi ina ili yonse ndipo palibe amene zimudandaulitse.</p> <p style="text-align: center;">INDE <input type="checkbox"/> AYI <input type="checkbox"/></p>



Ndikuvomerezana ndi wofufuza kuti akhoza kujambula mawu pa zokambirana ndi mafunso athu.

INDE AYI



Wofufuza adzagwiritsa ntchito mayankho anga kuchokera mu zokambirana ndi chithunzi changa polemba ma ripoti opanda dzina langa.

INDE AYI



Ndikudziwa kuti wofufuzasadzauza aliyense zokhudzana ndi zomwe ndafotokoza za kafukufuku koma ndikawafotokozero ndidzamva kupweteka ndekha kapena ena choncho adzayankhulana ndi ma membala a chipatala cha XXXXXXXXXX.

INDE AYI



Ndikufuna kutenga nawo mbali mu kafukufukuyu.

INDE AYI



Ndikudziwa kuti ndipitiriza kulandira thandizo ndi chisamaliro ku chipatala cha [REDACTED] ngakhale ndisatenge nawo mbali mu kafukufukuyu.

INDE AYI

Dzina la otenga mbali mu kafukufuku	Tsiku	Sayinani kapena kudinda ndi chala
Dzina la wofufuza	Tsiku	Sayinani

Chifomu chimodzi chidzaperekedwa kwa otenga nawo mbali mu kafukufuku ndipo china chidzasungidwa ndi wofufuza ku sukulu ya ukachenjede ya Lancaster ku England.

Appendix 22. Consent Form for caregivers (parents and guardians, English)

Consent Form for Caregivers



Project Title: Perceptions and experiences of adolescents living with HIV in Malawi

Name of Researcher: Nadine Ammon

Email: n.ammon@lancaster.ac.uk

Please tick each box

I have read / heard and understood the information sheet. I have been able to ask questions and I have received answers.	..
I understand that my child's participation is voluntary and that he/she is free to stop participating in this study at any time without giving any reason.	..
I am also aware that my decision to withdraw will not affect the medical or legal rights of my child.	..
If my child is participating in the focus group I understand that any information disclosed within the focus group remains confidential to the group, and he/she will not discuss the focus group with or in front of anyone who was not involved.	..
I understand that any information given by my child may be used in future reports, academic articles, publications or presentations by the researcher/s, but my child's personal information will not be included, and all reasonable steps will be taken to protect the anonymity of the participants involved in this project.	..
I understand that my child's name will not appear in any reports, articles or presentation made.	..
I understand that any interviews or focus groups will be audio-recorded and transcribed and that data will be protected on encrypted devices and kept secure.	..
I understand that data will be kept according to University guidelines for a minimum of 10 years after the end of the study.	..
I give permission for my child to take part in the above study.	..

I confirm that the parent/caregiver was given an opportunity to ask questions about the study, and all the questions asked have been answered correctly and to the best of my ability. I confirm that the individual has not been forced into giving consent, and the consent has been given freely and voluntarily.

Name of Participant		
Name of Parent/ Caregiver	Date	Signature or Fingerprint
Name of Researcher	Date	Signature

One copy of this form will be given to the participant and the original kept in the files of the researcher at Lancaster University.

Appendix 23. Consent Form for caregivers (parents and guardians, Chichewa)



**Chifomu cha chilolezo cha otenga nawo mbali mu kafukufuku
cha makolo ndi oyang'anira odwala**

Mutu wa Projekiti: Malingaliro ndi m'mene akukhalira achinyamata amene ali ndi kachilombo ka HIV ku Malawi

Dzina la Wofufuza: Nadine Ammon

Email: n.ammon@lancaster.ac.uk

Chongani m'malo mwapatsidwawo

Ndawerenga/ ndamva ndipo ndamvetsetsa zokhudzana ndi fomu iyi. Ndakwaniritsa kufunsa mafunso ndi kulandira mayankho.	..
Ndamvetsetsa kuti mwana wanga watenga mbali mwakuzipereka ndipo kuti ali ndi ufulu osiya kutenga pombali pa kafukufukuyu ameneyi nthawi iliyonse popanda kupereka zifukwa.	..
Ndiponso kuti kusiya kutenganawo mbali sikusintha kalikonse po landira chithandizo cha ku chipatala cha mwana wangayu.	..
Ngati mwana wanga atenga pombali pa zamagulu ndamvetsetsa kuti uthenga uliwonse wa magulu uzasala mothetzedwa pa gulu ndipo iye zazaloledwa kukambirana ndi gulu losa khuzidwa ndi kwali yense amene sanakhuzidwa.	..
Ndamvetsetsa kuti uthenga uliyonse opasidwa mwana wanga uzagwira ntchito kuti zikhazikitsidwe mu mabuku ophunzitsira ndi aukadaulo poyambira ndi akafukufuku, koma mwana wanga mauthenga ake sazakhuzidwa ndipo zifukwa sonse zizathengedwa kuteteza aliyense otenga pombali mu projekiti imeneyi.	..
Ndamvetsetsa kuti dzina la mwana wanga silidzaoneka mu ripoti lina lili lonse, kapena timabuku kapenanso kutchulidwa pa misonkhano.	..
Ndamvetsetsa kuti mafunso ena aliyonse or khuza magulu azajamulidwa ndi kusindikizidwa ndi kuti mauthenga azatetezedwa ndikusungidwa motetezeka.	..
Ndamvetsetsa kuti uthengau uzasungidwa molingana ndi ku sukulu ya ukachenjede kopitilira zaka 10 atatha ma phunziro.	..
Ndizapereka chilolezo kwa mwana wanga kutenga pombali pa kafukufuku.	..

Ndasimikiza kuti otenga pombali makolo/osamalira azapasidwa mwai ofunsa mafunso zokhudzana ndi kafukufukuyu, ndipo mafunso onse ofusidwa azayankhidwa bwino.

Ndasimikiza kuti anthu sazakamizidwa kupasidwa chilolezo ndi chilolezo chizaperekedwa mwaulele ndi mozipereka.

Dzina la otenga mbali mu kafukufuku		
Dzina la makolo/ woyang'anira	Tsiku	Sayinani kapena kudinda ndi chala
Dzina la wofufuza	Tsiku	Sayinani

Chifomu chimodzi chizaperekedwa kwa otenga nawo mbali mu kafukufuku ndipo china chidasungidwa ndi wofufuza ku sukulu ya ukachenjede ya Lancaster ku England.

Appendix 24. Consent Form for service providers



Consent Form for Service Providers

Project Title: Perceptions and experiences of adolescents living with HIV in Malawi

Name of Researcher: Nadine Ammon

Email: n.ammon@lancaster.ac.uk

Please tick each box

I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	..
I understand that my participation is voluntary and that I am free to withdraw at any time during my participation in this study and within 4 weeks after I took part in the study, without giving any reason. If I withdraw within 4 weeks of taking part in the study, my data will be removed. If I am involved in focus groups and then withdraw my data will remain part of the study. I understand that as part the focus group I will take part in, my data is part of the ongoing conversation and cannot be destroyed. I understand that the researcher will try to disregard my views when analysing the focus group data, but I am aware that this will not always be possible.	..
If I am participating in the focus group I understand that any information disclosed within the focus group remains confidential to the group, and I will not discuss the focus group with or in front of anyone who was not involved unless I have the relevant person's express permission.	..
I understand that any information given by me may be used in future reports, academic articles, publications or presentations by the researcher/s, but my personal information will not be included, and all reasonable steps will be taken to protect the anonymity of the participants involved in this project.	..
I understand that my name/my organisation's name will not appear in any reports, articles or presentation without my consent.	..
I understand that any interviews or focus groups will be audio-recorded and transcribed and that data will be protected on encrypted devices and kept secure.	..
I understand that data will be kept according to University guidelines for a minimum of 10 years after the end of the study.	..
I agree to take part in the above study.	..

Name of Participant

Date

Signature

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

Signature of Researcher/ person taking the consent: _____

Date: _____

One copy of this form will be given to the participant and the original kept in the files of the researcher at Lancaster University.

Appendix 25. Interpreter Confidentiality Form



Confidentiality Agreement for the interpretation
during research interviews

Name of Study:	Perceptions and experiences of adolescents living with HIV in Malawi
Study PI:	Nadine Ammon

In accordance with the Research Ethics Committee at Lancaster University (UREC), all participants in the above-named study are anonymised. Therefore, any personal information or any of the data generated or secured through interpretation will not be disclosed to any third party.

By signing this document, you are agreeing:

- to translate information objectively, fully and faithfully, to the best of your abilities.
- to understand that all information provided by participants is confidential, and you will not to pass on, divulge or discuss the contents of the interviews and focus group discussions to any third parties.
- to not derive any personal profit or advantage from any confidential information acquired during the interpretation.
- only act on the instructions of the University/researcher.
- to not employ any other person to carry out the work on your behalf.
- to have read and understand the foregoing agreement.

Your name and contact (block capitals)

Address at which the interpretation will take place

Your signature

Date

One copy of this form will be given to the interpreter and the original kept in the files of the researcher at Lancaster University.

Appendix 26. Topic guide for in-depth interview 1 with adolescents (English)



Topic Guide for IDI 1

Project Title: Perceptions and experiences of adolescents living with HIV in Malawi

Today's Date:

Location of interview:

Time started:

Time finished:

Interviewer's Name:

Translator's name:

Participant's Name:

Age:

Gender:

- Welcome participant
- Introductions
- Duration of the interview
- Reminder that they do not have to answer questions they do not want to, that they can withdraw at any point and report if they feel unwell
- Explain why this study is done and confidentiality issues
- Ask if there are questions
- Ask for permission to record the interview

[Start Recorder]

Establish Rapport

Before we begin, I would appreciate if you could tell me a bit about yourself. I will use questions, such as "Since when are you coming to the peer support group?"

1. Experience living with HIV
"Can you tell me about your experiences living with HIV?"
"What has changed over time?" (Probe about ART adherence, disclosure, joining peer support group)
2. HIV education
"Where did you first learn about HIV?" (Probe school, family, media, peer support group)
"What did you learn?" (Probe messages received)
3. Impact of HIV education on wellbeing
"How did those messages make you feel?"
"How do you feel about HIV now" (Probe change over time: since diagnosis, since attending peer support group and why change occurred)
4. Imagination of the HIV-virus
"How do you imagine the HIV-virus to look like?" (Probe size, features, habitat)

5. Drawing Activity (20-30 minutes)
 "There's some paper and pencils here. Could you please draw the HIV-virus for me so I can see what it looks like?"
 6. Participant's explanation of the visual product
 "Can you please explain your drawing?" (Probe size, colour, features such as eyes, mouth, teeth, habitat, number of viruses, flexibility, audibility)
 "Why do you think it looks like this?" (Probe source of information)
 "When and where did you see the HIV-virus like that?"
 "How has your image of HIV changed over time?" (Probe when and why change occurred)
 Emotions towards the visual product
 "How do you feel about this image?" (Probe "How does this image effect you?" and "How do you think others perceive HIV?")
 7. Link the image of HIV to antiretroviral therapy (ART)
 "What does the medicine you take do with the virus?" (Probe "What does ART do to you?" and "How does ART change your image of the virus?")
 8. Electron microscopic image of HIV and comparison to produced artwork
 "May I show you a photo of how the HIV virus looks like under a microscope?"
 (Showing electron microscopic image)
 "What do you think about it?" (Probe "When you compare your imagination with this photo, what do you see/think?")
 "How do you feel?" (Probe "When you compare your imagination with this photo, what do you feel?")
 9. Conclusion
 "Is there anything I left out that you think is important for us to include?"
 "Do you have any additional questions, comments, and/or concerns?"
 "How do you feel about this interview?"
- [Stop Recorder]
 - Thank participant for participation in study
 - Ask if participant want to keep the original artwork and if I am allowed to produce a scan of it
 - Agree on date for follow-up interview

Please note that this topic guide only outlines the main themes to be discussed with the participants and therefore it does not comprise the various prompts that may be used in addition to the questions included.

Appendix 27. Topic guide for in-depth interview 1 with adolescents (Chichewa)



Mutu woongolera wa mafunso ozama oyamba

Mutu wa Projekiti: Malingaliro ndi m'mene akukhalira achinyamata amene ali ndi kachilombo ka HIV ku Malawi

Tsiku la lero:

Malo opangira kafukufuku:

Nthawi yoyambira: Nthawi yomalizira:

Dzina la wofufuza:

Dzina la omasulira:

Dzina la otenga mbali mu kafukufuku:

Zaka:

Mwamuna/mkazi:

- Alandileni otenga mbali mu kafukufuku
- Malonje
- Mlingo wa kafukufuku
- Akumbutseni kuti akhoza kusayankha mafunso amene sakufuna kuyankha ndipo kuti akhoza kusiyira panjira ndi kumasuka kunena ngati sakupeza bwino.
- Fotokozani chifukwa chimene kafukufukuyu akuchitikira ndi zina zonse zokhudzana ndi chinsinsi.
- Funsani ngati pali mafunso.
- Pemphani chilolezo kuti mujambule mawu pogwiritsa ntchito makina ojambulira mawu.

[Yatsani makina ojambulira mawu]

Kulonjelana

Tisanayambe ndikhoza kusangalala mutandiuza zina zokhudza inu.

Ndidzagwiritsa ntchito mafunso monga "Munayamba liti kubwera ku gulu lothangatirana?"

1. M'mene mukukhalira ndi kachilombo ka HIV
"Ndiuzeni za m'menene mukukhalira ndi kachilombo ka HIV?"
"Chimene chasintha ndi chiyani patatha nthawi?" (Funsitsitsani za kamwedwe ka ma ART ndikuti akuwayanja bwanji, komanso funsitsani za zotsatira pambuyo poulula kuti ali ndi kachilombo, ndiponso zolowa nawo mu gulu la anthu amene ali ndi kachilombo ka HIV)
2. Maphunziro a kachilombo ka HIV
"Kodi munaphunzira kuti zokhudzana ndi kachilombo ka HIV poyamba?" (Funsitsitsani za sukulu, banja, manyuzipepala kapena pawayilesi, kapenanso kuchokera ku gulu lothangatirana)
"Kodi munaphunzira chiyani?" (Funsitsitsani mauthenga amene mwalandira)
3. Zotsatira za maphunziro a kachilombo ka HIV pa umoyo wabwino / zamene akulingalilira
"Kodi mauthenga amenewo anakupangitsani kumva bwanji?"

“Kodi panopo mukumva bwanji kulingana ndi za kachilombo ka HIV?” (Funsitsitsani ngati pali kusintha kuli konse patatha nthawi kuyambira pamene munadziwa kuti muli ndi kachilombo, ndiponso kuyambira pamene munalowa mu gulu lothangatilana)

4. Malingaliro a maonekedwe a kachilombo ka HIV
“Kodi mumaganiza kuti kachilombo ka HIV kamaoneka bwanji?” (Funsitsitsani za kukula kwake, maonekedwe ake, ndi malo amene chimakhala)
5. Ntchito yojambula (mphindi 20-30)
“Pali mapepala ndi mapenisulo apa. Mundijambulile m’mene mukuganizira maonekedwe a kachilombo ka HIV kuti ndione m’mene kamaonekera?”
6. Otenga nawo mbali kufokozera chithunzi chawo
“Fotokozani chithunzi chanu?” (Funsitsitsani za kukula, kwake, mtundu, maonekedwe, monga maso, pakamwa, pamalo okhala, chiwerengero cha tizilombo, kumasuka kwake ndi mamvekedwe ake)
Zomvaimva zokhudzana ndi chithunzichi
“Mukumva bwanji zokhudzana ndi chinthuchi?” (Funsitsitsani “Chithunzichi chikukhudzana bwanji?” ndipo “Mukuganiza bwanji za m’mene ena amaganizira za kachilombo ka HIV?”)
7. Lumikizitsani maonekedwe a kachilombo ka HIV ndi mankhwala otalikitsa moyo ama ART
“Kodi mankhwala amene mukumwa amachita chiyani ku kachilombo ka HIV?”
(Funsitsitsani “Kodi ma ART amachita chiyani kwa inu?” ndipo “Kodi ma ART anasintha bwanji malingaliro anu amaonekedwe a kachilombo ka HIV?”)
8. Maonekedwe a kachilombo ka HIV pa makina ndi kusiyantsa ndi chithunzi chimene chajambulidwa
“Ndingakuonetseni chithunzi cha m’mene kachilombo kamaonekera pa makina?”
(Onetsani chithunzi cha kachilombo ka HIV cha pa makina.)
“Mukuganiza chiyani za chimenechi?”
(Funsitsitsani “Kodi mukalinganiza malingaliro anu ndi chithunzi ichi, mukuona kapena mukuganiza chiyani?”)
“Mukumva bwanji?” (Funsitsitsani “Kosi mukalinganiza malingaliro anu ndi chithunzi ichi, mukumva bwanji?”)
9. Pomaliza
“Kodi chilipo china chimene sitinakambiranepo koma ndi chofunikira kuti tikambirane?”
“Kodi muli ndi mafunso ena owonjezera, ndemanga kapena madandaulo?”
“Kodi mukumva bwanji kukhudzana ndi kafukufukuyu?”
 - [Thimitsani makina ojambulira mawu]
 - Athokozeni otenga nawo mbali mu kafukufuku
 - Funsani ngati otenga nawo mbali akufuna asunge chithunzi komanso ngati angalore wofufuza kuti achijambule ndikuchisunga.
 - Gwirizanani za tsiku loti mudzafunsi dwenso mafunso polondoloza kafukufukuyu.

Chonde dziwani izi uwu ndi m’ndandanda chabe mwachidule wa mitu ikulu ikulu imene tidzakambirana ndi otenga nawo mbali pakhoza kukhalabe zina zimene tingadzakambirane zimene sitinalembe.

Topic Guide for follow-up In-depth Interview

Project Title: Perceptions and experiences of adolescents living with HIV in Malawi

Today's Date:

Location of interview:

Time started:

Time finished:

Interviewer's Name:

Translator's name:

Participant's Name:

Age:

Gender:

- Welcome participant
- Introductions
- Duration of the interview
- Reminder that they do not have to answer questions they do not want to, that they can withdraw at any point and report if they feel unwell
- Explain why this study is done and confidentiality issues
- Ask if there are questions
- Ask for permission to record the interview

[Start Recorder]

Establish Rapport

Before I start with the interview, I will use questions, such as "How was your time since we met 2 weeks ago?"

1. Thoughts and feelings about experience of last interview
"Since we met at the last interview, has anything changed in how you view and think about HIV?" (Probe "What has changed?")
2. Recap on the produced drawing (Show drawing)
"When you have a look again at your drawing, what do you think about it now?"
"How do you feel about it?"
"Would you still draw the same image?" (Probe "Why?")
3. Comparison of drawing to electron microscopic image of HIV
(Show again the electron microscopic image of HIV)
"When you compare your drawing again to the electron microscopic photo of the HIV-virus, what do you think about it now?" "How do you feel about it?"

4. Local term used for HIV

“In Chichewa the term for HIV is Kachilombo. What does Kachilombo mean?”

“When do people use the term Kachilombo?” (Probe “How do people use the term Kachilombo?”)

“How does Kachilombo look like?”

5. Participant’s opinion concerning HIV education

“Do you think children should know how the virus really looks like?” (Probe “Why?”)

“Who should teach them?” (Probe “Why?”, “At which age?”, “Why at this age?”)

“What would you improve in the HIV education material, which is currently used?”
(Probe “Why?”)

6. Conclusion

“Is there anything I left out that you think is important for us to include?”

“Do you have any additional questions, comments, and/or concerns?”

“How do you feel about this interview?”

- [Stop Recorder]
- Thank participant for participation in study
- Agree on date for focus group discussion and ask again for permission to show the drawing or scan of it during this discussion without disclosing the artist’s name.

Please note that this topic guide only outlines the main themes to be discussed with the participants and therefore it does not comprise the various prompts that may be used in addition to the questions included.

Appendix 29. Topic guide for follow-up in-depth interview with adolescents
(Chichewa)



Mutu woongolera wa mafunso ozama achiwiri

Mutu wa Projekiti: Malingaliro ndi m'mene akukhalira achinyamata amene ali ndi kachilombo ka HIV ku Malawi

Tsiku la lero:

Malo opangira kafukufuku:

Nthawi yoyambira: Nthawi yomalizira:

Dzina la wofufuza:

Dzina la omasulira:

Dzina la otenga mbali mu kafukufuku:

Zaka:

Mwamuna/mkazi:

- Alandileni otenga mbali mu kafukufuku
- Malonje
- Mlingo wa kafukufuku
- Akumbutseni kuti akhoza kusayankha mafunso amene sakufuna kuyankha ndipo kuti akhoza kusiyira panjira ndi kumasuka kunena ngati sakupeza bwino.
- Fotokozani chifukwa chimene kafukufukuyu akuchitikira ndi zina zonse zokhudzana ndi chinsinsi.
- Funsani ngati pali mafunso
- Pemphani chilolezo kuti mujambule mawu pogwiritsa ntchito makina ojambulira mawu.

[Yatsani makina ojambulira mawu]

Kulonjelana

Tisanyambe, ndigwiritsa ntchito mafunso monga “Nyengo yanu inali bwanji chionelane masabata awiri apitawo?”

1. Maganizo ndi zomvaimva zokhudzana ndi mafunso oyamba
“Kodi pali kusintha kwina kuil konse kokhudzana ndi m'mene mukuganizira za kachilombo ka HIV chikumanireni pakukumana kwathu m'mbuyomu?”
(Funsitsitsani “Kodi chimene chasintha ndi chiyani?”)
2. Kubwereza kukambirana za chithunzi (Onetsani chithunzi)
“Mukachionanso chithunzi chanu, kodi mutha kuganiza chiyani panopo?”
“Mukumva bwanji za chimenechi?”
“Kodi mukhoza kujambulanso chithunzi monga chomwechi mutapatsidwa mwayi woti mutero?” (Funsitsitsani “Chifukwa chiyani?”)

3. Kusiyanyitsa kwa chithunzi cha kachilombo ka HIV pa makina ndi chojambulidwa (Onetsaninso chithunzi cha kachilombo ka HIV cha pa makina)
 “Mukalinganiza chithunzi chanu cha kachilombo ndi chithunzi chojambulidwa pa makina, mukuganiza chiyani za chimenechi panopo?”
 “Mukumva bwanji za chimenechi?”

4. Dzina la mu Chichewa la HIV
 “Mu Chichewa dzina la HIV ndi Kachilombo. Kodi kachilombo zimatanthauza chiyani?”
 “Kodi anthu amagwiritsa ntchito liu loti kachilombo liti?”
 (Funsitsitsani “Kodi anthu amagwiritsa ntchito liu loti kachilombo bwanji?”)
 “Kodi kachilombo kamaoneka bwanji?”

5. Maganizo a otenga nawo mbali okhudzana ndi maphunziro a HIV
 “Mukuganiza kuti ana amayenera kudziwa maonekedwe a kachilombo a HIV m’mene kamaonekera pa makina?” (Funsitsitsani “Chifukwa chiyani?”)
 “Amayenera kuwaphunzitsa ndi ndani?” (Funsitsitsani “Chikukwa chiani?”, “Pa msinkhu wanjiji?”, “Chifukwa chiyani pa msinkhu uwu?”)
 “Ndi chiyani chimene inu mukhoza kusintha ndi kupititsa patsogolo mu mabuku amaphunziro a kachilombo ka HIV amene akugwiritsidwa ntchito panopo?”
 (Funsitsitsani “Chifukwa chiyani?”)

6. Pomaliza
 “Kodi chilipo china chimene sitinakambiranepo koma ndi chofunikira kuti tikambirane?”
 “Kodi muli ndi mafunso ena owonjezera, ndemanga kapena madandaulo?”
 “Kodi mukumva bwanji kukhudzana ndi kafukufukuyu?”
 - [Thimitsani makina ojambulira mau]
 - Athokozeni otenga nawo mbali mu kafukufuku
 - Gwirizanani za tsiku ndi nthawi yokumana pa zokambirana za gulu ndipo mufunsenso chilolezo chodzagwiritsa ntchito chithunzi pa zokambirana za pagulu posatchulapo dzina la ojambula.

Chonde dziwani izi uwu ndi m’ndandanda chabe mwachidule wa mitu ikulu ikulu imene tidzakambirana ndi otenga nawo mbali pakhoza kukhalabe zina zimene tingadzakambirane zimene sitinalemba.

Appendix 30. Topic guide for focus group discussions with adolescents (English)

Topic Guide for FGD with adolescents



Project Title: Perceptions and experiences of adolescents living with HIV in Malawi

Today's Date:

Location of interview:

Time started:

Time finished:

Moderator's Name:

Participants' Names:

Ages:

Gender:

- Welcome participants
- Introductions
- Duration of the discussion
- Reminder that they do not have to answer questions they do not want to, that they can withdraw at any point and report if they feel unwell
- Explain why this study is done and confidentiality issues
- Ask if there are questions
- Ask for permission to record the interview

[Start Recorder]

Establish Rapport

Before we begin, I would appreciate if you could tell me a bit about yourselves. I will use questions, such as "Since when are you coming to the [REDACTED] clinic?"

1. Present drawings of adolescents living with HIV (Show drawings)
"These are the drawings that adolescents living with HIV have produced during the interviews I conducted. The drawings show how they imagine the HIV-virus to look like."
"When you have look at them, what do you think?"
"How do you feel about it?"
"How do you think other groups or people might visualise HIV?"
2. Link of imagination and wellbeing
"How does the way you visualise HIV affect how you feel about the virus?"
3. Local term used for HIV
"In Chichewa the term for HIV is Kachilombo. What does Kachilombo mean?"
"When do people use the term Kachilombo?" (Probe "How do people use the term Kachilombo?")
"How does Kachilombo look like?"
4. Comparison of drawings to electron microscopic image of HIV
(Show an electron microscopic image of HIV)

“When you compare these drawings to the electron microscopic image of the HIV-virus, what do you think about it?” “How do you feel about it?”

5. Participants’ opinion concerning HIV education

“Do you think adolescents should know how the HIV-virus looks like under the electron microscope?” (Probe “Why?”, “Which adolescents? HIV-positive adolescents, HIV-negative adolescents?”)

“Who should teach them?” (Probe “Why?”, “At which age?”, “Why at this age?”)

“What would you improve in the HIV education material, which is currently used?” (Probe “Why?” and “Where – at school, at the clinic, in the community, in the media”.)

6. Conclusion

“Is there anything I left out that you think is important for us to include?”

“Do you have any additional questions, comments, and/or concerns?”

“How do you feel about this group discussion?”

- [Stop Recorder]
- Thank participants for participation in study.

Please note that this topic guide only outlines the main themes to be discussed with the participants and therefore it does not comprise the various prompts that may be used in addition to the questions included.

Appendix 31. Topic guide for focus group discussions with adolescents (Chichewa)



Mutu woongolera wa zokambilana za pa gulu ndi achinyamata

Mutu wa Projekiti: Malingaliro ndi m'mene akukhalira achinyamata amene ali ndi kachilombo ku Malawi

Tsiku la lero:

Malo opangira kafukufuku:

Nthawi yoyambila:

Nthawi yoyambira:

Dzina la omasulira:

Mayna a otenga nawo mbali mu kafukufuku:

Zaka:

Mwamuna/mkazi:

- Alandileni otenga mbali mu kafukufuku
- Malonje
- Mlingo wa so kambirana
- Akumbutseni kuti akhoza kusayankha mafunso amene sakufuna kuyankha ndipo kuti akhoza kusiyira panjira ndi kumasuka kunena ngati sakupeza bwino.
- Fotokozani chifukwa chimene kafukufukuyu akuchitikira ndi zina zonse zokhudzana ndi chinsinsi.
- Funsani ngati pali mafunso
- Pemphani chilolezo kuti mujambule mawu pogwiritsa ntchito makina ojambulira mawu.

[Yatsani makina ojambulira mawu]

Kulonjerana

Tisanayambepo, ndikufuna ndikupempheni mundiuze mwachidule zokhudza inuyo. Ndidzagwiritsa ntchito mafunso ngati “Mwakhala mukubwera ku chpatala cha [REDACTED] kuyambira liti?”

1. Onetsani zithunzi zimene achinyamata amene ali ndi kachilombo ka HIV anajambula (Onetsani zithunzi)
“Izi ndi zithunzi zimene achinyamata amene ali ndi kachilombo anajambula pamene timawafunsa mafunso. Zithunzizi zikuonetsa m'mene achinyamatawa amaganizira za maonekedwe a kachilombo.”
“Mukazionanso zithunzizi, mukuganiza chiyani?”
“Mukumva bwanji za chimenechi?”
“Mukuganiza kuti magulu ena a anthu amalingalira bwanji za kachilombo ka HIV?”
2. Lumikizitsani malingaliro ndi umoyo wabwino / zamene akulingalilira
“Kodi malingaliro anu aza kachilombo ka HIV amakukhudzani bwanji m'mene mumamvera za kachilombo ka HIV?”

3. Dzina la mu Chichewa la HIV

“Mu Chichewa dzina la HIV ndi Kachilombo. Kodi kachilombo zimatanthauza chiyani?”

“Kodi anthu amagwiritsa ntchito liu loti kachilombo liti?”

(Funsitsitsani “Kodi anthu amagwiritsa ntchito liu loti kachilombo bwanji?”)

4. Kusiyantsa kwa chithunzi cha kachilombo ka HIV pa makina ndi chojambulidwa

(Onetsani chithunzi cha pa makina cha HIV)

“Mukalinganiza chithunzi chanu cha kachilombo ndi chithunzi chojambulidwa pa makina, mukuganiza chiyani za chimenechi panopo?”

“Mukumva bwanji za chimenechi panopa?”

5. Maganizo a otenga nawo mbali okhudzana ndi maphunziro a HIV

“Mukuganiza kuti ana amayenera kudziwa maonekedwe eni eni a kachilombo a HIV?”

(Funsitsitsani “Chifukwa chiyani?”, “Achinyamata ati? Omwe ali ndi kachilombo kapena amene alibe kachilombo?”)

“Amayenera kuwaphunzitsa ndi ndani?”

(Funsitsitsani “Chifukwa chiyani?”, “Pa msinkhu wanji?”, “Chifukwa chiyani pa msinkhu uwu?”)

“Ndi chiyani chimene inu mukhoza kusintha ndi kupititsa patsogolo mu mabuku amaphunziro a kachilombo ka HIV amene akugwiritsidwa ntchito panopo?” (Funsitsitsani

“Chifukwa chiyani?” ndipo “Kuti – ku sukulu, ku chipatala, mu dera, ma nyuzipepala, pa waillesi ndi pa intaneti?”)

6. Pomaliza

“Kodi chilipo china chimene sitinakambiranepo koma ndi chofunikira kuti tikambirane?”

“Kodi muli ndi mafunso ena owonjezera, ndemanga kapena madandaulo?”

“Kodi mukumva bwanji ndi zokhudzana zokambirana za pagulu?”

- [Thimitsani makina ojambulira mawu]
- Athokozeni otenga nawo mbali mu kafukufuku.

Chonde dziwani izi uwu ndi m’ndandanda chabe mwachidule wa mitu ikulu ikulu imene tidzakambirana ndi otenga nawo mbali pakhoza kukhalabe zina zimene tingadzakambirane zimene sitinalembe.

Appendix 32. Topic guide for focus group discussion with service providers



Topic Guide for FGD with service providers

Project Title: Perceptions and experiences of adolescents living with HIV in Malawi

Today's Date:

Place:

Time started:

Time finished:

Moderator's Name:

Participants' Names:

Ages:

Gender:

- Welcome participants
- Introductions
- Duration of the discussion
- Reminder that they do not have to answer questions they do not want to, that they can withdraw at any point and report if they feel unwell
- Explain why this study is done and confidentiality issues
- Ask if there are questions
- Ask for permission to record the interview

[Start Recorder]

Establish Rapport

Before we begin, I would appreciate if you could tell me a bit about yourselves. I will use questions, such as "Since when are you working at the [REDACTED] clinic?" or "What was your motivation to start working at the [REDACTED] clinic?"

1. Present drawings of adolescents living with HIV (Show drawings)
"These are the drawings that adolescents living with HIV have produced during the interviews I conducted with them. The drawings show how they imagine the HIV-virus to look like."
"When you have look at them, what do you think?"
"How would you interpret these drawings?"
"How do you think other groups people might visualise HIV?"
2. Impact of HIV imaginations
"What could be the impact of these imaginations on the adolescents?"
"How could the way we visualise HIV affect how we feel about the virus?"

3. Local term used for HIV

“In Chichewa the term for HIV is Kachilombo. What does Kachilombo mean?”

“When do people use the term Kachilombo?” (Probe “How do people use the term Kachilombo?”)

“How could we link this term to the drawings?”

4. Comparison of drawings to electron microscopic image of HIV

(Show an electron microscopic image of HIV)

“When you compare these drawings to the electron microscopic image of the HIV-virus, what do you think about it?”

“How do you feel about it?”

“When comparing their drawings to the electron microscopic image of HIV, the adolescents explained xxx. What are your thoughts on this?”

“Where do you think these imaginations come from?” (Probe cultural factors)

5. Participants’ opinion concerning HIV education

“Where do adolescents learn about HIV?” (Probe “What do they learn? In which way? At which age?”)

“What can be done to change the way young people visualise and discuss HIV?”

“How can educational materials promote a more realistic and less stigmatising view of HIV?”

“Do you think educational material/visual aids should include the photo of the electron microscopic HIV-virus? (Probe “Why?”, “How?”, “Which adolescents? HIV-positive adolescents, HIV-negative adolescents?)

“Who should teach them?” (Probe “Why?”, “At which age?”, “Why at this age?”)

“What would you change in the HIV education material, which is currently used?”

(Probe “Why?” “Where – at school, at the clinic, in the community, in the media”.)

“Do you have recommendations for policy makers, for clinicians, support staff?”

6. Conclusion

“Is there anything I left out that you think is important for us to include?”

“Do you have any additional questions, comments, and/or concerns?”

“How do you feel about this group discussion?”

- [Stop Recorder]
- Thank participants for participation in study.

Please note that this topic guide only outlines the main themes to be discussed with the participants and therefore it does not comprise the various prompts that may be used in addition to the questions included

Appendix 33. Research timeline

	2021							2022												2023					
	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	
Identification of 2 research assistants/translators	█																								
Recruitment (16 ALHIV)		█	█	█	█	█																			
Meeting with caregivers and ALHIV for consent/ assent				█	█	█																			
Recruitment (5 service providers)							█																		
Data collection: 32 IDIs, 16 drawings by ALHIV				█	█	█	█																		
Data collection: 4 FGDs with ALHIV							█																		
Data collection: 1 FGD with 5 service providers							█																		
Transcription and data analysis				█	█	█	█	█	█	█	█	█													
Writing of thesis drafts												█	█	█	█	█	█	█	█	█	█	█	█	█	█
Submission of final thesis																								█	

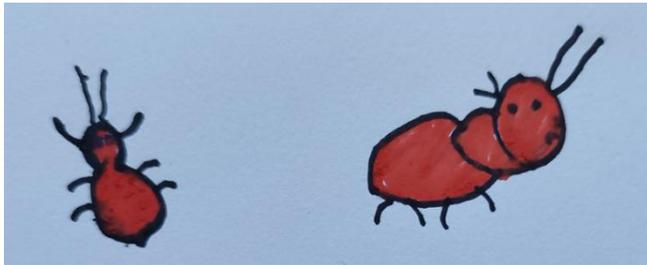
Appendix 34. Sample of coding (textual data)

Interview with Mkango, male, age 12

M = Mkango (Interviewee); NA = Nadine Ammon (Interviewer)

Transcript	Code
<p>NA: What can you remember what you were told when you got to know that you are HIV positive? M: She (Mom) said that I have HIV and that I need to take medication daily and I should not fear HIV, I can achieve whatever I want to achieve in life, that's why I am taking the medication.</p>	<p>Encouragement by mother helps for adhering to ART.</p>
<p>NA: And when you got this message from your Mom, how did this make you feel? M: I was worried. NA: Why? M: I thought I was missing something in my body.</p>	<p>Worried, feeling of emptiness after disclosure.</p>
<p>NA: What about the medicine you are taking? Can you tell me a little bit about it? M: I am taking ARVs for the virus to sleep, my body to be strong and that in future I may achieve my goals.</p>	<p>ART puts the HIV-virus to sleep, making him strong to function.</p>
<p>NA: Ok. And what does the medicine do with these viruses? M: The medication makes the virus to sleep all the time. When it wakes up it makes us feel sick. But the medication makes it to sleep, it is very strong.</p>	<p>If not adherent to ART, the HIV-virus wakes up, resulting in sickness.</p>
<p>NA: How do you imagine the size of the HIV virus? M: I know it is a virus, someone cannot see it with the eyes. NA: And if we use a machine to enlarge it, how may it look like? M: Ah, I don't know.</p>	<p>HIV is not visible with the eye.</p>
<p>NA: Where is it located in the body? M: In our blood. NA: Is it one or are there more? M: More.</p>	<p>Multiple viruses in the blood.</p>
<p>NA: What else does it (HIV virus) have on the face? M: Mouth, what makes us to be sick, because it eats our body, then we get sick.</p>	<p>He imagines the HIV-virus to have a face. The mouth is used to eat the body, making him sick.</p>
<p>NA: Is it able to make some sound? M: Maybe. (He laughs) NA: Why maybe? M: Because there are many, not a single one. They may have some disagreements. NA: And when do you think they have disagreements? M: Maybe when they are eating, they may quarrel. NA: What is the medicine doing with the virus? M: The medicine makes the viruses to sleep, so they cannot quarrel. If there is no medication they can quarrel, because they are awake. NA: What are they doing when they are sleeping? M: They are powerless when they are sleeping, so they cannot do anything.</p>	<p>He imagines the HIV-viruses having (audible?) disagreements over food. Those disagreements occur when ART is not taken, as ART makes the viruses powerless.</p>
<p>NA: How do feel, when you compare your drawing and this photo? M: I am happy, because now I know how the virus looks like.</p>	<p>Happy to know how the HIV-virus looks like under the electron microscope. Knowledge he was looking for.</p>

Appendix 35. Drawings completed by the eight female adolescent participants



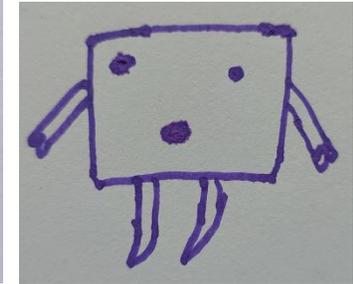
Lydia, 13



Thalandira, 13



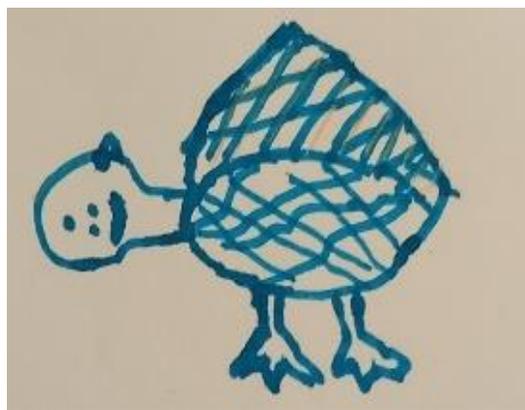
Shanita, 14



Patuma, 14



Chisomo, 15



Amina, 16



Ndazona, 17

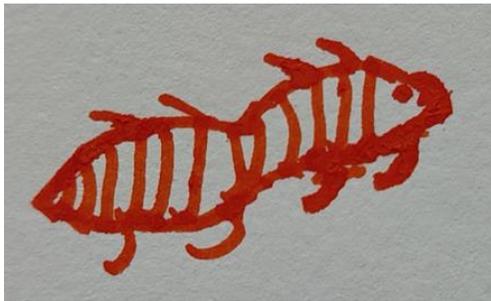
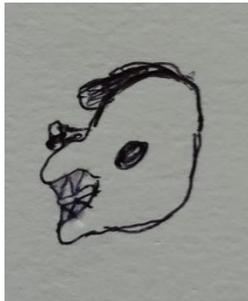


Anne, 18

Appendix 36. Drawings completed by the eight male adolescent participants



Mishello, 10



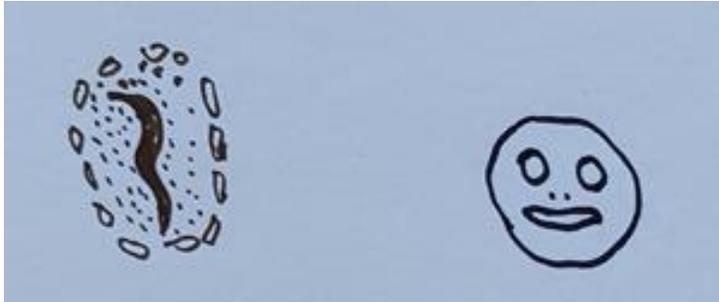
Mkango, 12



Woimba, 12



Lion, 13



Elmore, 15



Jonathan, 15



Lovemore, 16



Daligo, 18