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'You are not alone' -
The Role of Social Relationships in Engagement in Care for Adolescents Living with Perinatally Acquired HIV in Western Kenya

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An abstract of

a thesis submitted to the Faculty of the

Rollins School of Public Health of Emory University

in partial fulfillment of the requirements for the degree of

Master of Public Health

in the Hubert Department of Global Health

2022

Abstract

‘You are not alone’ - The Role of Social Relationships in Engagement in Care for Adolescents Living with Perinatally Acquired HIV in Western Kenya

By Taren L McGray

Introduction. Adolescents with perinatally acquired HIV (APHIV) are a relatively novel and understudied population, despite their high morbidity and mortality compared to other people living with HIV (PLHIV). The distinct psychosocial challenges APHIV face suggest that social relationships may be an important factor in their engagement in or disengagement with care. To better understand the lived experiences of APHIV and inform APHIV care and support, the Kenya Medical Research Institute (KEMRI) conducted a mixed-methods study. The purpose of the present study was to examine the role that social relationships play in how APHIV in Western Kenya engage with and disengage from care, with the aim of informing efforts to improve the support of APHIV in Western Kenya.

Methods. This thesis comprises the secondary analysis of qualitative data collected by KEMRI from July 2019 and August 2021. Transcripts from interviews with APHIV (n=14), their caregivers (n=15), and providers (n=16), 6 focus group discussions (FGDs) with APHIV, and 2 FGDs with caregivers were analyzed thematically using a constant comparative methodology and grounded theory-based approach using an adapted Socio-Ecological Model (SEM) framework.

Results. Supportive, involved, and caring relationships with friends, family, and romantic or sexual partners improved APHIV engagement in care, often through the intermediary of improved mental health. Having these positive relationships encouraged APHIV to desire to live and therefore adhere to ART and attend clinic visits. Microsystem influences, such as taking ART with others, adherence follow-up, and having close relationships, were most influential in helping APHIV feel loved, normal, and less alone. Meso- and exo-system contexts were also important in creating an enabling or prohibitive environment for APHIV engagement in care, including caregivers’ interactions with other people in APHIV’s lives, having to visit relatives over school holidays, and the support group environment. Macrosystem challenges related to stigma were found to pervade each level, particularly the individual-level, where self-stigma influenced many of APHIV’s personal strategies for managing their care.

Conclusions. APHIV engagement in care is largely influenced through direct interactions and the socio-environmental contexts within which these relationship exist. Interventions should focus on developing strategies to strengthen the level of support felt by APHIV through their friends, peers, teachers, caregivers, and family to improve their motivation for engaging in care This may include tools to improve counseling, training, and education of those who interact with APHIV. An important aspect of these interventions involves teaching those who interact with APHIV how to mitigate socioenvironmental barriers to engagement in care, such as peer pressure, stigma, and disclosure-related challenges.

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Acknowledgements:

I would be remiss to write about the importance of social relationships without gratuitously acknowledging my own. First, I would like to thank my Committee Co-Chairs, Kate Winskell and Gaëlle Sabben for their immense feedback and support throughout this process. I cannot express enough how grateful I am for their thoughtful reviews of my many, many drafts, most of which were way longer than they should have been, and for always lending a critical listening ear when I needed to organize my thoughts aloud. A special thanks goes to Kate, who, as my advisor, has been a constant source of encouragement and support over the past two years, always reminding me to stay grounded and focused on exploring experiences where I could learn the skills I need to succeed in my career.

I am also incredibly grateful for Ken Ondeng'e and Calvin Mbeda, for inviting me to participate in their research as well as for their invaluable insights along the way. This paper would not be possible without their support. My appreciation also extends to the entire KEMRI team. While I may not have had the pleasure of meeting everyone, it is truly those who designed KEMRI's study and collected and managed the data who made my place in this possible. More thanks goes to Emma Clevenger, my thesis partner, for co-developing our codebook and working through challenges together, and Monique Hennink, for teaching me just about everything I know about qualitative research.

I would also like to extend my sincerest gratitude to each participant of this study for their honesty and vulnerability. This includes the caregivers, providers, and particularly the adolescents who bravely shared their stories. Through participation, they have generously offered their experiences to help improve the support felt by countless APHIV across Western Kenya, and to consequently save lives.

Finally, I would like to thank my friends and family who have been my biggest social supports throughout this crazy process, especially Rachel Straub, Michelle Varraveto, and Andrew Kobin, for their endless encouragement and advice in my most stressed moments, and, of course, for reminding me to take breaks. I also feel obliged to acknowledge my dog, Ruby, for the unconditional love and comfort.

My deepest thanks goes to my mom, for never being surprised by my success. A special thanks also goes to my brother, who taught me I could do anything; who made sure that everyone in his life felt loved, valued, and worthy of living, except himself. I wish he could be here to see this. It is my greatest hope that this work can be used to inform interventions that help make the world feel a little bit bigger, and the people in it feel a little less alone.

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List of Abbreviations:

ALHIV: Adolescent Living with HIV

APHIV: Adolescents Living with Perinatally Acquired HIV

ART: Antiretroviral Therapy

HCC: HIV Care Continuum

HIV: Human Immunodeficiency Virus

PLHIV: People Living with HIV

SEM: Socio-Ecological Model

SDH: Social Determinants of Health

SSA: Sub-Saharan Africa

Chapter 1: Introduction

1.1 Background

The highest AIDS-related mortality rate across the globe occurs in adolescents (ages 10-19), with the largest cohort (88%) of adolescents living with HIV (ALHIV) residing in sub-Saharan Africa (SSA) (UNICEF, 2021a). Kenya, with 91,634 ALHIV, is amongst the top seven countries with the most ALHIV (National AIDS and STI Control Programme (NASCOP), 2020; National AIDS Control Council, 2020; UNICEF, 2021b). The increased number of ALHIV is largely driven by the increase in adolescents with perinatally acquired HIV (APHIV) (Lowenthal et al., 2014). Perinatally acquired HIV refers to HIV transmitted from mother to child during pregnancy, childbirth, or breastfeeding. For decades, children with perinatally acquired HIV rarely survived to adolescence, but the development of and increased access to antiretroviral therapy (ART) has increased the life expectancy of these children, thus making APHIV a relatively novel population (Winskell et al., 2016). Worldwide, there are roughly 1.3 million APHIV, an estimated 79% of whom live in SSA (Gitahi et al., 2020; Slovgrove et al., 2018).

The increased survival of children with perinatally acquired HIV prompted the evolution of pediatric HIV into a chronic illness. The complex clinical histories of APHIV, paired with the unique psychosocial challenges of growing up with HIV, lead to a myriad of unprecedented challenges (Lowenthal et al., 2014; Mofenson & Cotton, 2013; Salou et al., 2016). APHIV experience worse HIV-related health outcomes, compared to both children and adults living with HIV, including higher morbidity and mortality as well as lower rates of virological suppression (Dassi Tchoupa Revegue et al., 2021; Luseno et al., 2017). Although there was a 30% decline in global HIV-related deaths between 2005 and 2012, HIV-related deaths rose among all ALHIV by 50% (UNAIDS, 2013). This is partially thought to be the result of unique barriers APHIV face in engaging with care. Higher rates of ALHIV mortality in low- and middle-income countries, including SSA, suggest that characteristics of care, including ART regimens and level of engagement, differ across contexts (Slogrove et al., 2018) .

While diagnosis and disclosure typically occur simultaneously for adults and adolescents with behaviorally acquired HIV, most children and adolescents with perinatally acquired HIV are disclosed to some time following diagnosis, often several years later. Children and younger adolescents lack the autonomy and understanding to care for themselves, especially prior to disclosure, making the caregiver an essential link in the care of children and younger adolescents. APHIV also face unique mental health challenges, in addition to psychosocial issues common to any age group living with HIV (Casale et al., 2019; Frigati et al., 2020; Lowenthal et al., 2014). Literature suggests that failure of health services to address the specific needs of ALHIV is at least partially responsible for the disproportionately poor clinical outcomes and high mortality rates among youth living with HIV compared to adults (World Health Organization, 2013). However, studies that conflate adolescents with behaviorally and perinatally acquired HIV may miss critical information about the unique challenges of each.

1.2 Social Relationships

Despite numerous studies showing the importance of social relationships for adults with HIV, there are limited data for ALHIV (Abramowitz et al., 2009; Damulira et al., 2019). However, the importance of socialization during adolescence in shaping self-identity and autonomy points to the high potential for social factors to influence ALHIV experiences and health. Psychosocial factors, including perceived stigma, self-efficacy, self-esteem, and perceived social support influence how ALHIV disclose their status to peers. The ability to self-disclose is an important part of adolescent wellbeing and a unique aspect of the HIV Care Continuum (HCC) for ALHIV (Nöstlinger et al., 2015). Evidence further suggests that understanding social factors is critical for designing prevention and tailoring health services to reduce adverse disease outcomes and further HIV transmission (Silva-Santisteban et al., 2013). Much of this research excludes the unique social experiences of APHIV or conflates them with those of adolescents with behaviorally acquired HIV. APHIV are more likely to be full or partial orphans, and their families often learn their status before or concurrently with the child, which differs greatly from the experiences of adolescents with behaviorally acquired HIV.

The influence of social relationships on APHIV engagement in care can be elucidated through the Socio-Ecological Model (SEM) (Bronfenbrenner, 1979). Literature suggests that social relationships can facilitate the self-efficacy for care management, ultimately improving retention in care and ART adherence, but also present APHIV with HIV-related stigma and discrimination, which can hinder engagement in care (Williams et al., 2017). Other common social determinants of health (SDH) for APHIV in SSA that are nested within the SEM include orphanhood, poverty, and inconsistent guardianship, all of which amplify the risk of behavioral and psychiatric problems among APHIV (Lowenthal et al., 2014). Despite recognition that psychosocial interventions are influential in optimizing engagement in care, psychosocial needs among ALHIV in SSA typically receive little attention due to the prioritization of acute medical and economic issues (Lowenthal et al., 2014; Williams et al., 2017). There has yet to be an SEM framework applied to APHIV.

1.3 Need for Evaluation

Limited data on and understanding of the unique experiences of APHIV has led to insufficient guidance for caregivers, providers, and policy-makers on how best to support APHIV (Dowshen & D'Angelo, 2011; Hussen et al., 2017). While recent studies attempt to explore the lived experiences of ALHIV, many rely on quantitative and/or clinical data, which limits the ability to capture the emic youth perspective, focuses on older APHIV, neglecting valuable experiences about transitioning through puberty and high school, or aggregates behaviorally and perinatally acquired cases, thus excluding the unique nature of perinatally acquired HIV. The vastly different epidemiology of adolescent HIV in the context of SSA additionally limits the generalizability of study findings from North America and Europe, where much of APHIV research has previously been focused (Abramowitz et al., 2009; Le Prevost et al., 2018). In Kenya, the establishment of youth friendly clinical services has been prioritized, but there is limited understanding of the experiences and needs of Kenyan APHIV. Any mention of perinatally acquired HIV is absent from the Strategic Framework (National AIDS Control Council, 2020).

1.4 Kenya Medical Research Institute

In order to better understand the lived experiences of APHIV, the Kenya Medical Research Institute (KEMRI), conducted a mixed-methods study. The study, led by Kenneth Ondeng’e and KEMRI colleagues, sought to investigate the unique challenges of APHIV in Western Kenya, including disclosure, coping mechanisms, parental loss, and psychosocial needs. KEMRI employed clinical and demographic surveys amongst APHIV, and individual interviews and focus group discussions with APHIV, their caregivers, and providers across Kisumu and Homabay counties in Kenya (Kenya Medical Research Institute, 2019). KEMRI then invited our research team from the Emory Rollins School of Public Health to participate in data analysis.

1.5 Purpose Statement

This study sought to examine the role that social relationships play in how APHIV in Western Kenya engage with and disengage from care, using an adapted Socio-Ecological Model (SEM) framework. Within the scope of this research, aspects of engagement in care that are relevant to APHIV include: ART adherence, clinic attendance, and achievement and maintenance of viral load suppression. Social relationships assessed in this research feature caregivers, other family, peers and friends, school staff, romantic and sexual partners, and ALHIV in support groups.

The objectives of this study are to: (1) understand the role that social relationships at school, home, and in the community play in supporting APHIV; (2) understand the unique mental health experiences of APHIV as they relate to engagement in care; (3) examine how caregivers and providers of APHIV understand their role in supporting APHIV's engagement with care; and (4) inform strategies to support APHIV engagement in care.

Chapter 2: Literature Review

2.1 Background

Currently, the highest AIDS-related mortality rate across the globe occurs in adolescents (ages 10-19). Approximately 1.75 million adolescents live with HIV worldwide, with 32,000 dying from AIDS-related causes in 2020 alone (UNICEF, 2021a). Currently, the largest cohort of adolescents living with HIV (ALHIV) is in sub-Saharan Africa (SSA), with an estimated 88%, or 1.5 million, of the world's ALHIV population residing there (UNICEF, 2021a). Kenya, with approximately 139,000 children living with HIV and 91,634 ALHIV, is amongst the seven countries with the highest ALHIV populations (National AIDS and STI Control Programme (NASCOP), 2020; National AIDS Control Council, 2020; UNICEF, 2021b).

Adolescents have become a prominent sub-group among PLHIV, largely driven by the increase in adolescents with perinatally acquired HIV (APHIV) (Lowenthal et al., 2014). Perinatally acquired HIV refers to HIV transmitted from mother to child during pregnancy, childbirth, or breastfeeding. For decades, children born with perinatally acquired HIV rarely survived to adolescence. The development of and increased access to antiretroviral therapy (ART) has increased the life expectancy of these children, thus making APHIV a relatively novel population (Winskell et al., 2016). Worldwide, there are roughly 1.3 million APHIV, an estimated 79% of whom live in SSA (Gitahi et al., 2020; Slogrove et al., 2018).

2.2 Perinatally acquired HIV

Prevention of mother-to-child transmission was introduced in Africa in 2004 (Luseno et al., 2017). In the same year, access to pediatric ART expanded, resulting in a decline in HIV-related mortality among children with perinatally acquired HIV (Lowenthal et al., 2014). This increased survival rate prompted the evolution of pediatric HIV into a chronic illness.

Children with perinatally acquired HIV experience HIV prior to having a fully developed immune system, which produces a distinct histology complicating clinical care and leading to high rates of virological failure as adolescents (Lowenthal et al., 2014; Mofenson & Cotton, 2013; Salou et al., 2016). The complex clinical histories of APHIV, paired with the unique psychosocial challenges of growing up with HIV, lead to a myriad of unprecedented challenges.

Although there was a 30% decline in global HIV-related deaths between 2005 and 2012, HIV-related deaths rose among adolescents living with both perinatally and behaviorally acquired HIV by 50% (UNAIDS, 2013). Compared to both children and adults living with HIV, APHIV experience worse HIV-related health outcomes, including higher morbidity and mortality as well as lower rates of virological suppression (Dassi Tchoupa Revegue et al., 2021; Luseno et al., 2017). Increased susceptibility of APHIV to adverse health outcomes is thought to be the result of unique barriers APHIV face in engaging with care. Rates of HIV-related mortality among adolescents are significantly higher in low- and middle- income countries, including in SSA, compared to North America and Europe, suggesting that APHIV interact with care differently in these contexts, partly due to older regimens that demand greater adherence (Slogrove et al., 2018).

2.3 HIV Care Continuum.

The HIV Care Continuum (HCC) refers to an internationally recognized public health model outlining the stages of HIV care. It consists of 5 steps: diagnosis, linkage to care, retention in care, adherence to ART, and viral suppression. The HCC typically guides how public health researchers measure global progress in the response to HIV, as well as how clinicians monitor engagement in care for PLHIV. While the original framework was depicted as a linear progression, many now recognize that the HCC is dynamic and bidirectional (Kay et al., 2016).

Much of the research on the HCC has been conducted in adults from resource-rich countries (Zanoni et al., 2016). However, APHIV interact with the HCC in unique ways, and the context-specific nature of HIV health services and sociocultural differences limits the translation of those findings to regions such as SSA. Literature additionally reveals that HIV service models geared towards adults living with HIV are not transferrable to ALHIV, given the vastly different lived experiences and social realities of adolescents (Skovdal & Belton, 2014).

While all PLHIV enter the HCC upon diagnosis, a critical difference is that diagnosis and disclosure occur simultaneously for adults and adolescents with behaviorally acquired HIV while most youth with perinatally acquired HIV are disclosed to some time following diagnosis, often several years later. This means the role of caregivers is critical for how APHIV interact with the HCC. Children and younger adolescents lack the autonomy and understanding to take care of themselves, especially prior to the age of disclosure, making the caregiver an essential link between youth and their HIV care.

Disclosure.

Disclosure is an important HCC step for APHIV, influencing their motivation for ART adherence and achieving viral suppression. Disclosure practices in SSA are mainly conducted one-on-one, but can sometimes occur during group sessions involving other PLHIV (Dahourou et al., 2018). Disclosure is universally recognized as a process rather than a single event. Full disclosure is considered to have occurred when the individual knows that they have HIV/AIDS and are able to provide information about HIV care and modes of transmission. Partial disclosure is common among children and adolescents living with HIV (Dassi Tchoupa Revegue et al., 2021). Guidelines put forth by the World Health Organization (WHO) recommend that the process of disclosure should begin at age 7 and be complete by age 12 (Gitahi et al., 2020).

Despite this, the median age of disclosure for APHIV across SSA is 13 years (Dahourou et al., 2018). In Kenya, only 36% of APHIV know their status by the age of 12, suggesting that delayed disclosure is a common practice there (Gitahi et al., 2020). Dahourou et al. (2018) points out that disclosure to APHIV is complex due to numerous caregiver-related barriers, such as parental fears that the APHIV will break secrecy around their parents' HIV status as well as parental feelings of guilt in passing HIV to their child.

Caregiver Role.

Engagement in care for children and younger adolescents with HIV requires the active participation of caregivers as mediators between their treatment and their experiences with HIV (Skovdal & Belton, 2014). Self-Determination Theory (SDT), when applied to PLHIV, indicates that those who have greater autonomy in planning their own treatment are more likely to adhere to ART and be motivated to improve their health behaviors. This has strong implications for children and younger adolescents living with HIV, who naturally lack autonomy due to their age. Feelings of autonomous motivation in youth may be improved through autonomy support (Kennedy et al., 2004). Skovdal et al. (2020) suggests that caregiver's attentiveness to the future needs of their child, sense of obligation, and ability to care for the child are key motivators of youth engagement with HIV services.

There is limited literature on the balancing act between autonomy and support for APHIV, with existing literature emphasizing the complexity of APHIV and caregiver interactions (Kang et al., 2008). Caregivers of APHIV typically know the status of their child prior to the child knowing, and thus are responsible for caring for the APHIV before they are disclosed to. Yet self-governance remains an important aspect of APHIV's transition into adulthood (Kang et al., 2008). There is a need for additional understanding of APHIV autonomy in SSA.

Mental Health of APHIV.

In addition to the psychosocial issues common to any age group living with HIV, APHIV face unique mental health challenges. APHIV have a high risk of exposure to a myriad of psychological stressors, including the severe HIV-related illness and/or death of their parents and siblings, responsibility for younger siblings or other ill family members, stigma and discrimination, and being confronted with mortality and an uncertain future at a very young age (Frigati et al., 2020; Lowenthal et al., 2014). Worldwide, over 50% of APHIV are orphans, which has also been linked to poor health outcomes (Lowenthal et al., 2014). APHIV also often suffer from various comorbidities, such as cardiovascular disease, neurodevelopmental delay, skin disease, and/or visual impairments. These stressors limit the development of internal protective mechanisms and leave youth ill-prepared to cope with challenges later in life, which is one hypothesis for the increased risk for mental health challenges among APHIV (Frigati et al., 2020).

A South African study found that, compared to peers without HIV, ALHIV had poorer functional competence, self-concept, and motivation, as well as higher levels of depression, disruptive behavior, attention-deficit hyperactivity disorder symptoms, and clinically significant anger (Frigati et al., 2020). Compared to adults with HIV, ALHIV are uniquely vulnerable to the impact of stigma and discrimination, both well-established barriers to adherence and engagement in care, as well as strong correlates of negative mental health outcomes (Casale et al., 2019; Damulira et al., 2019). Studies suggest that adolescents and young adults living with HIV are at a higher risk for depression, anxiety, and decreased ART adherence (Casale et al., 2019; Damulira et al., 2019; Frigati et al., 2020).

Although it is well acknowledged that adolescents with both perinatally and behaviorally acquired HIV represent a high-risk population for suicidal ideation and attempts, little is known about risk and protective factors for suicidality (Casale et al., 2019). Moreover, studies that conflate behaviorally and perinatally acquired HIV may miss critical information. A multivariate analysis found that APHIV in South Africa were significantly less likely to report depression, anxiety, and internalized stigma compared to adolescents with behaviorally acquired HIV (Sherr et al., 2018). Luseno et al. (2017) suggests that older adolescents with perinatally acquired HIV were more motivated to engage in care, while older adolescents with behaviorally acquired HIV felt self-blame, guilt, and regret that resulted in low enrollment in care. However, both Sherr et al. (2018) and Luseno et al. (2017) suggest potential confounders for their findings, such as age and gender. A strong understanding of specific mental health needs of adolescents with behaviorally and perinatally acquired HIV can lead to improved mental health support to help ALHIV achieve optimal health outcomes (Frigati et al., 2020).

2.4 Engagement in care.

Children born with HIV who survive to adolescence are often disengaged from care (never initiated or dropped out of care) which can lead to the presentation of serious illness (Luseno et al., 2017). Adverse health outcomes in APHIV are thought to be associated with delayed HIV diagnosis and ART initiation, delayed disclosure, poor ART adherence, and poor retention in care (Dassi Tchoupa Revegue et al., 2021). Poor engagement in care has life-long consequences: individuals who are not virally suppressed as adolescents are less likely to achieve viral suppression as adults, which is a major contributor to HIV-related mortality and transmission to others (Hussen et al., 2017; Kapogiannis et al., 2020).

Literature suggests that the failure of health services to address the specific needs of ALHIV, leading to late diagnosis and poor adherence to ART, is among the causes of the disproportionately poor clinical outcomes and high mortality rates among youth living with HIV compared to adults (World Health Organization, 2013). APHIV in middle- and low-income countries are typically older at ART initiation and have lower CD4 counts and higher rates of impaired height compared to those in high-income countries. In 2018, SSA had the highest ART attrition rate compared to other regions across the globe (Slogrove et al., 2018).

Barriers to engagement.

Common barriers to engagement in care for ALHIV include side effects from HIV drugs, pill burden, lack of comprehensive and accurate knowledge about HIV, and limited access to clean water and nutritious food, as well as the psychosocial barriers discussed above (Lowenthal et al., 2014; Luseno et al., 2017). Poor engagement in care among ALHIV is additionally thought to be attributable to the low prioritization of ALHIV in national HIV plans, a lack of accessible and acceptable HIV services for adolescents, and the complex psychosocial needs of adolescents (Winskell et al., 2016; Kapogiannis et al., 2020; Damulira et al., 2019; Dowshen & D'Angelo, 2011; Skovdal & Belton, 2014).

Adolescence is a critical developmental period in which puberty and rapid brain growth lead to new behaviors and transitioning roles (Viner et al., 2012; Nöstlinger et al., 2015). Living with HIV during adolescence causes many physiological, social, and behavioral changes, challenges, and needs (Kaunda-Khangamwa et al., 2020; Winskell et al., 2016). With limited research disaggregating ALHIV by mode of acquisition, the impact of growing up with HIV versus contracting HIV behaviorally on social development, engagement in care, and health outcomes is equally limited.

2.5 Socio-Ecological Model

Influences on engagement in care for APHIV can be elucidated through the Socio-Ecological Model (SEM), a conceptual framework introduced by Urie Bronfenbrenner (Bronfenbrenner, 1979). The SEM theorizes that individual behavior is nested within a network of systems representative of relationships, interactions, and contexts that influence the individual (Figure 1). The SEM is a common tool for exploring major contributors to health and designing and implementing multi-level prevention strategies.

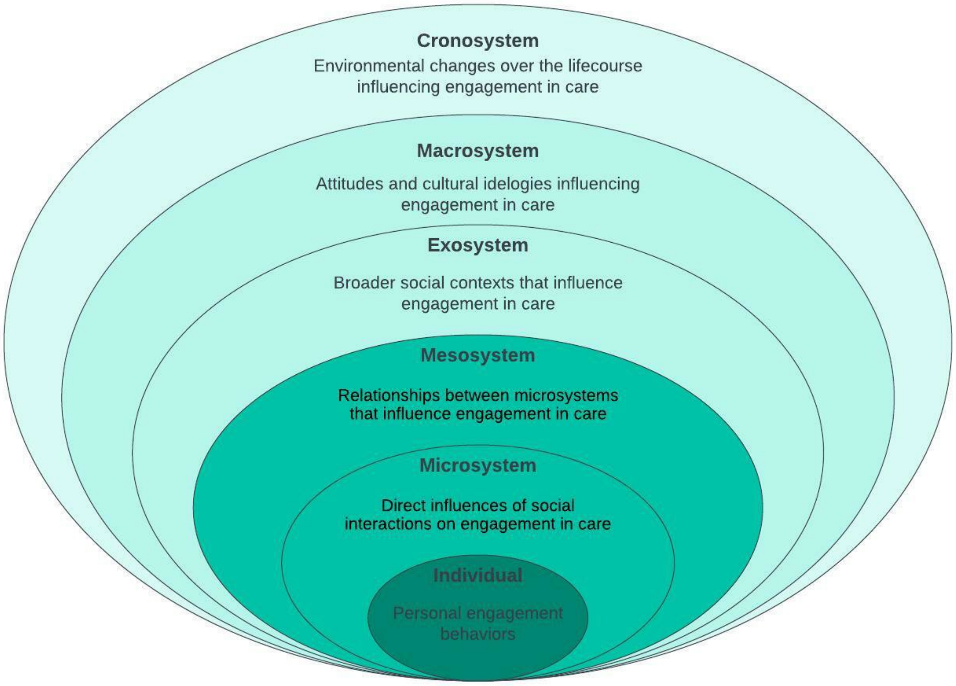

Figure 1. Socio-Ecological Model, adapted from Bronfenbrenner, 1979

The SEM and modified versions thereof have been used to explain HIV risk contexts, particularly to examine influences on HIV-related behaviors for pregnant women, men who have sex with men, and other vulnerable populations (Baral et al., 2013). It has also been adapted and applied to ALHIV. A meta-ethnographic study found that barriers to engagement in care for ALHIV in SSA largely fell at the individual-level, including personal strategies for adherence (Williams et al., 2017). However, Williams et al., (2017) also suggested that social relationships can facilitate the self-efficacy of ALHIV to manage their care, which ultimately improves retention in care and adherence to ART. This paper additionally found that stigma pervaded each level of the SEM, hindering engagement with the HCC at multiple stages. This suggests that psychosocial interventions should be prioritized to help optimize ALHIV engagement in care (Williams et al., 2017). There has yet to be an SEM framework applied specifically to APHIV.

2.6 Social Determinants of APHIV Health.

Social Determinants of Health (SDH) are defined by WHO as "the conditions in which people are born, grow, live, work and age" (World Health Organization, 2022). Despite the recognition that adolescence is a key developmental stage in the life course, SDH research often primarily focuses on early childhood development and neglects the importance of adolescent SDH. SDH occurring during adolescence interact with psychological and biological transitions to influence how individuals grow and function as productive adults (Viner et al., 2012).

Adolescence is a critical time for risk-factor reduction and enhancement of protective factors to help adolescents actuate their full potential and reach optimal health throughout the life course (Viner et al., 2012). Accordingly, the health and wellbeing of ALHIV is inextricable from their experiences with SDH, which vary by gender, family relationships, schooling, and involvement in teen support groups (Kaunda-Khangamwa et al., 2020; Viner et al., 2012).

A study conducted in England found that HIV status alone was not associated with depression, but predictors of depression among ALHIV included male sex, death of one/both parents, school exclusion, and lower social functioning (Le Prevost et al., 2018). This indicates the importance of understanding how SDH interact with the serostatus of ALHIV to influence their engagement in care and overall health. Additional studies in SSA suggest that family, school, community, and health facility environments are all key for improving diagnosis, linkage to care, and retention in care (Luseno et al., 2017; Williams et al., 2017).

In SSA, common SDH for ALHIV include orphanhood, poverty, and inconsistent guardianship, which amplify the risk of behavioral and psychiatric problems among ALHIV, including post-traumatic stress disorder, depression, and severe anxiety. Despite the commonality of these factors and their influence on access to HIV care, ART adherence, and ultimately viral suppression, psychosocial needs among ALHIV in SSA typically receive little attention due to the struggle to address more acute medical and economic issues (Lowenthal et al., 2014).

Social Support as a Determinant of APHIV Engagement in Care.

The role of supportive social relationships as an adolescent SDH is robustly supported by literature (Kaunda-Khangamwa et al., 2020; Viner et al., 2012; Williams et al., 2017; Winskell et al., 2016). Social relationships comprise social support structures, supportive family and kinship relationships, and social participation, all of which may be influenced by stigma and discrimination.

Social support, a major protective factor against adverse health outcomes for individuals living with HIV, is commonly defined as a relationship involving an exchange of resources that enhance wellbeing (Damulira et al., 2019). Social support can have a positive impact on HIV-related morbidity through promotion of ART adherence, ability to disclose to sexual partners, improved mental health and overall mood, and increased comfort disclosing HIV status to others (Abramowitz et al., 2009; Damulira et al., 2019). Social support for PLHIV can also include reminders to refill ART; providing transportation, food, and/or money; and encouraging and listening to PLHIV (Damulira et al., 2019; Skovdal et al., 2020). Evidence suggests that monitoring social factors is critical in understanding preventive interventions and ways to improve appropriate care and treatment to reduce adverse disease outcomes and HIV transmission (Silva-Santisteban et al., 2013).

Despite numerous studies showing the importance of social relationships for adults with HIV, there are limited data on these relationships for ALHIV (Abramowitz et al., 2009; Damulira et al., 2019). The importance of socialization during adolescence in shaping self-identity and autonomy points to the high potential for social factors to influence the experiences and health of ALHIV (Nöstlinger et al., 2015). A qualitative study in SSA investigated the psychosocial factors influencing how ALHIV disclose their status to peers and found a number of challenges relating to perceived stigma, self-efficacy, self-esteem, and perceived social support. The ability to feel comfortable enough with others to self-disclose is also an important part of adolescent wellbeing and a unique piece of the HCC for ALHIV (Nöstlinger et al., 2015).

The role of social supports for APHIV is even less researched. One study found that youth with behaviorally acquired HIV reported having significantly more friends than youth with perinatally acquired HIV, but received less support from family in accessing care. General perceived support in both cases was a predictor of depression(Abramowitz et al., 2009). Literature suggests that strong caregiver and community support are associated with better adherence among ALHIV in SSA (Winskell et al., 2016).

Family cohesion looks different for APHIV because their parents, and sometimes siblings, are often also living with HIV or have died from AIDS. Family cohesion is an important factor in ALHIV's comfort with disclosing their status, which in turn increases the support they experience from family. Lack of family cohesion is linked to limited access to care, counselling, and ART adherence (Damulira et al., 2019). With perinatally acquired HIV, often the families learn their status before or concurrently with the child, which means that caregivers may have limited education about HIV and must navigate their own status before focusing on their child's health.

2.7 Need for Evaluation.

Limited data on and understanding of the unique experiences of APHIV has led to insufficient guidance for caregivers, providers, and policy-makers on how best to support APHIV (Hussen et al., 2017; Dowshen & D'Angelo, 2011). While recent studies attempt to explore the lived experiences of ALHIV, many rely on quantitative and/or clinical data, which limits the ability to capture the emic youth perspective, focuses on older APHIV, neglecting valuable experiences about transitioning through puberty and high school, or aggregates behaviorally and perinatally acquired cases, thus excluding the unique nature of perinatally acquired HIV. The vastly different epidemiology of adolescent HIV in the context of SSA additionally limits the generalizability of study findings from North America and Europe, where much of APHIV research has previously been focused (Abramowitz et al., 2009; Le Prevost et al., 2018). In Kenya, the establishment of youth-friendly clinical services has been prioritized, but there is limited understanding of the experiences and needs of Kenyan APHIV. Any mention of perinatally acquired HIV is absent from the Strategic Framework (National AIDS Control Council, 2020).

2.8 Kenya Medical Research Institute

In order to better understand the lived experiences of APHIV, the Kenya Medical Research Institute Center for Global Health Research (KEMRI CGHR), conducted a mixed-methods study. The study, led by Kenneth Ondeng'e and KEMRI colleagues, sought to investigate the unique challenges of APHIV in Western Kenya, including disclosure, coping mechanisms, parental loss, and psychosocial needs. The KEMRI team employed clinical and demographic surveys amongst APHIV, and individual interviews and focus group discussions with APHIV, their caregivers, and providers across Kisumu and Homabay counties in Kenya (Kenya Medical Research Institute, 2019). KEMRI then invited our research team from the Emory Rollins School of Public Health to participate in data analysis.

2.9 Purpose Statement

This study sought to examine the role that social relationships play in how APHIV in Western Kenya engage with and disengage from care, using an adapted Socio-Ecological Model (SEM) framework. Within the scope of this research, aspects of engagement in care that are relevant to APHIV include: ART adherence, clinic attendance, and achievement and maintenance of viral load suppression. Social relationships assessed in this research feature caregivers, other family, peers and friends, school staff, romantic and sexual partners, and ALHIV in support groups.

The objectives of this study are to: (1) understand the role that social relationships at school, home, and in the community play in supporting APHIV; (2) understand the unique mental health experiences of APHIV as they relate to engagement in care; (3) examine how caregivers and providers of APHIV understand their role in supporting APHIV's engagement with care; and (4) inform strategies to support APHIV engagement in care.

Chapter 3: Manuscript

3. 1 Abstract.

Introduction. Adolescents with perinatally acquired HIV (APHIV) are a relatively novel and understudied population, despite their high morbidity and mortality compared to other people living with HIV (PLHIV). The distinct psychosocial challenges APHIV face suggest that social relationships may be an important factor in their engagement in or disengagement with care. To better understand the lived experiences of APHIV and inform APHIV care and support, the Kenya Medical Research Institute (KEMRI) conducted a mixed-methods study. The purpose of the present study was to examine the role that social relationships play in how APHIV in Western Kenya engage with and disengage from care, with the aim of informing efforts to improve the support of APHIV in Western Kenya.

Methods. This thesis comprises the secondary analysis of qualitative data collected by KEMRI between July 2019 and August 2021. Transcripts from individual interviews with APHIV (n=14), their caregivers (n=15), and providers (n=16), 6 focus group discussions (FGDs) with APHIV, and 2 FGDs with caregivers (n=2) were analyzed thematically using a constant comparative methodology and grounded theory-based approach using an adapted Socio-Ecological Model (SEM) framework.

Results. Supportive, involved, and caring relationships with friends, family, and romantic or sexual partners improved APHIV engagement in care, often through the intermediary of improved mental health. Having these positive relationships encouraged APHIV to desire to live and therefore adhere to ART and attend clinic visits. Microsystem influences, such as taking ART with others, adherence follow-up, and having close relationships, were most influential in helping APHIV feel loved, normal, and less alone. Meso- and exo-system contexts were also

important in creating an enabling or prohibitive environment for APHIV engagement in care, including caregivers' interactions with other people in APHIV's lives, having to visit relatives over school holidays, and the support group environment. Macrosystem challenges related to stigma were found to pervade each level, particularly the individual-level, where self-stigma influenced many of APHIV's personal strategies for managing their care.

Conclusions. APHIV engagement in care is largely influenced through direct interactions and the socio-environmental contexts within which these relationship exist. Interventions should focus on developing strategies to strengthen the level of support felt by APHIV through their friends, peers, teachers, caregivers, and family to improve their motivation for engaging in care This may include tools to improve counseling, training, and education of those who interact with APHIV. An important aspect of these interventions involves teaching those who interact with APHIV how to mitigate socioenvironmental barriers to engagement in care, such as peer pressure, stigma, and disclosure-related challenges.

3. 2 Introduction.

Background.

The highest AIDS-related mortality rate across the globe occurs in adolescents (ages 10-19), with the largest cohort (88%) of adolescents living with HIV (ALHIV) residing in sub-Saharan Africa (SSA) (UNICEF, 2021). Kenya, with approximately 139,000 children with HIV and 91,634 ALHIV, is amongst the top seven countries with the most ALHIV (National AIDS and STI Control Programme (NASCOP), 2020; National AIDS Control Council, 2020; UNICEF, 2021b). Adolescents have become a substantial sub-group among people living with HIV (PLHIV), partially driven by the increase in adolescents with perinatally acquired HIV (APHIV) (Lowenthal et al., 2014). Perinatally acquired HIV refers to HIV transmitted from mother to child during pregnancy, childbirth, or breastfeeding. For decades, children with perinatally acquired HIV rarely survived to adolescence, but the development of and increased access to antiretroviral therapy (ART) has increased the life expectancy of these children, thus making APHIV a relatively novel population (Winskell et al., 2016). Worldwide, there are roughly 1.3 million APHIV, an estimated 79% of whom live in SSA (Gitahi et al., 2020; Slogrove et al., 2018).

Increased survival of children with perinatally acquired HIV prompted the evolution of pediatric HIV into a chronic illness. The complex clinical histories of APHIV, paired with the unique psychosocial challenges of growing up with HIV, lead to a myriad of unprecedented challenges (Lowenthal et al., 2014; Mofenson & Cotton, 2013; Salou et al., 2016). APHIV experience worse HIV-related health outcomes, compared to both children and adults living with HIV, including higher morbidity and mortality as well as lower rates of virological suppression (Dassi Tchoupa Revegue et al., 2021; Luseno et al., 2017). Although there was a 30% decline in global HIV-related deaths between 2005 and 2012, HIV-related deaths rose among all ALHIV by 50% (UNAIDS, 2013). This is thought to be the result of unique barriers APHIV face in engaging with care. Higher rates of ALHIV mortality in low- and middle-income countries, including SSA, suggest that characteristics of care, including ART regimens and level of engagement, differ across contexts (Slogrove et al., 2018).

APHIV Engagement in Care.

While diagnosis and disclosure occur simultaneously for adults and adolescents with behaviorally acquired HIV, most children and adolescents with perinatally acquired HIV are disclosed to some time following diagnosis, often several years later. Children and younger adolescents lack the autonomy and understanding to care for themselves, especially prior to disclosure, making the caregiver an essential link in the care of children and younger adolescents. APHIV also face unique mental health challenges, in addition to psychosocial issues common to any age group living with HIV (Casale et al., 2019; Frigati et al., 2020; Lowenthal et al., 2014). Poor mental health can result in disengagement from care among APHIV, which has life-long consequences: adolescents who are not virally suppressed are less likely to achieve viral suppression as adults (Hussen et al., 2017; Kapogiannis et al., 2020). Adverse health outcomes in APHIV are thought to be associated with delayed HIV diagnosis and ART initiation, delayed disclosure, poor ART adherence, and poor retention in care (Dassi Tchoupa Revegue et al., 2021). Literature suggests that failure of health services to address the specific needs of ALHIV is at least partially responsible for the disproportionately poor clinical outcomes and high mortality rates among youth living with HIV compared to adults (World Health Organization, 2013). However, studies that conflate adolescents with behaviorally and perinatally acquired HIV may miss critical information about the unique challenges of each.

The influence of social relationships on APHIV engagement in care can be elucidated through the Socio-Ecological Model (SEM) (Kilanowski, 2017). Literature suggests that social relationships can facilitate the self-efficacy for care management, ultimately improving retention in care and ART adherence, but also present APHIV with HIV-related stigma and discrimination, which can hinder engagement in care (Williams et al., 2017). Other common social determinants of health for APHIV in SSA that are nested within the SEM include orphanhood, poverty, and inconsistent guardianship, all of which amplify the risk of behavioral and psychiatric problems among APHIV (Lowenthal et al., 2014). Despite recognition that psychosocial interventions are influential in optimizing engagement in care, psychosocial needs among APHIV in SSA typically receive little attention due to the prioritization of acute medical and economic issues (Williams et al., 2017; Lowenthal et al., 2014). There has yet to be an SEM framework applied to APHIV.

Social support.

The role of supportive social relationships as an adolescent SDH is robustly supported by literature (Kaunda-Khangamwa et al., 2020; Viner et al., 2012; Williams et al., 2017; Winskell et al., 2016). Social relationships encompass social support structures, supportive family and kinship relationships, and social participation, all of which may be influenced by stigma and discrimination (Viner et al., 2012).

Social support, a major protective factor against adverse health outcomes for PLHIV, is commonly defined as a relationship involving an exchange of resources that enhance wellbeing (Damulira et al., 2019). Social support for PLHIV can include adherence reminders; transportation to clinic; provision of food and/or money; and encouraging and listening to PLHIV (Damulira et al., 2019; Skovdal et al., 2020). Literature suggests that social support positively impacts HIV-related morbidity through improved ART adherence, increased ability to disclose and subsequently safer sex practices, improved mental health, and increased comfort disclosing to others (Abramowitz et al., 2009; Damulira et al., 2019).

Despite numerous studies showing the importance of social relationships for adults with HIV, there are limited data for ALHIV (Abramowitz et al., 2009; Damulira et al., 2019). However, the importance of socialization during adolescence in shaping self-identity and autonomy points to the high potential for social factors to influence ALHIV experiences and health (Nöstlinger et al., 2015). Nöstlinger et al. (2015) found that psychosocial factors, including perceived stigma, self-efficacy, self-esteem, and perceived social support, influence how ALHIV disclose their status to peers. The ability to self-disclose is an important part of adolescent wellbeing and a unique aspect of the Health Care Continuum for ALHIV (Nöstlinger et al., 2015). Evidence further suggests that understanding social factors is critical for designing prevention and tailoring health services to reduce HIV incidence and adverse disease outcomes (Silva-Santisteban et al., 2013). Much of this research excludes the unique social experiences of APHIV or conflates them with those of adolescents with behaviorally acquired HIV.

Across all ALHIV, perceived support is a predictor of depression (Abramowitz et al., 2009). US youth with behaviorally acquired HIV reported having significantly more friends than youth with perinatally acquired HIV, but received less support from family in accessing care (Abramowitz et al., 2009). Luseno et al. (2017) found that, among older adolescents (age 15-19) in Kenya, APHIV have greater social supports than adolescents with behaviorally acquired HIV, although numerous potential confounders were noted.

Literature suggests that strong caregiver and community support are associated with better adherence among ALHIV in SSA (Winskell et al., 2016). Lack of family cohesion and limited familial support are additionally linked to limited access to care and counselling as well as poor ART adherence (Damulira et al., 2019). Family structure looks different for APHIV because their parents, and sometimes siblings, are often also living with HIV or have died from AIDS. Moreover, with perinatally acquired HIV, families often learn their status before or concurrently with the child, which means that caregivers may have limited education about HIV and must navigate their own status before focusing on their child's health.

Need for Evaluation

Limited data on and understanding of the unique experiences of APHIV has led to insufficient guidance for caregivers, providers, and policy-makers on how best to support APHIV (Hussen et al., 2017; Dowshen & D'Angelo, 2011). While recent studies attempt to explore the lived experiences of ALHIV, many rely on quantitative and/or clinical data, which limits the ability to capture the emic youth perspective, focuses on older APHIV, neglecting valuable experiences about transitioning through puberty and high school, or aggregates behaviorally and perinatally acquired cases, thus excluding the unique nature of perinatally acquired HIV. The vastly different epidemiology of adolescent HIV in the context of SSA additionally limits the generalizability of study findings from North America and Europe, where much of APHIV research has previously been focused (Abramowitz et al., 2009; Le Prevost et al., 2018). In Kenya, the establishment of youth friendly clinical services has been prioritized, but there is limited understanding of the experiences and needs of Kenyan APHIV. Any mention of perinatally acquired HIV is absent from the Strategic Framework (National AIDS Control Council, 2020).

Kenya Medical Research Institute

In order to better understand the lived experiences of APHIV, the Kenya Medical Research Institute Center for Global Health Research (KEMRI CGHR), conducted a mixed-methods study. The study, led by Kenneth Ondeng'e and KEMRI colleagues, sought to investigate the unique challenges of APHIV in Western Kenya, including disclosure, coping mechanisms, parental loss, and psychosocial needs. The KEMRI team employed clinical and demographic surveys amongst APHIV and interviews and focus group discussions with APHIV, their caregivers, and providers across Kisumu and Homabay counties in Kenya (Kenya Medical Research Institute, 2019). KEMRI then invited our research team from the Emory Rollins School of Public Health to participate in data analysis.

Purpose Statement

This study sought to examine the role that social relationships play in how APHIV in Western Kenya engage with and disengage from care, using an adapted Socio-Ecological Model (SEM) framework. Within the scope of this research, aspects of engagement in care that are relevant to APHIV include: ART adherence, clinic attendance, and achievement and maintenance of viral load suppression. Social relationships assessed in this research feature caregivers, other family, peers and friends, school staff, romantic and sexual partners, and ALHIV in support groups.

The objectives of this study are to: (1) understand the role that social relationships at school, home, and in the community play in supporting APHIV; (2) understand the unique mental health experiences of APHIV as they relate to engagement in care; (3) examine how caregivers and providers of APHIV understand their role in supporting APHIV's engagement with care; and (4) inform strategies to support APHIV engagement in care.

3.3 Methodology.

Study design. As part of a larger study conducted by KEMRI, our study uses a qualitative design to examine the role of social relationships on APHIV engagement in care. The use of qualitative research was important to ensure that the emic perspective was captured and new ideas could arise spontaneously.

Study site. Data collection was conducted at health facilities located in Kisumu and Homabay Counties in western Kenya. This location reflects the high prevalence of HIV in the former Nyanza region (19.9%), the substantially higher ALHIV population in Kisumu and Homabay counties (13,988 and 15,323, respectively) compared to other counties in Kenya, and the high rate of MTCT in the two counties (20% and 17%, respectively) (National AIDS Control Council, 2016). Facilities were selected on the basis of having many youth patients and pre-existing youth-friendly platforms to improve the chance of recruiting eligible participants. Homabay was chosen in addition to Kisumu because of the high rurality, which balanced Kisumu's more urban population. Study participants were recruited from youth centers offering comprehensive HIV care in Kisumu, western Kenya. Five youth centers offering comprehensive HIV care served as study sites: Kisumu County Hospital (KCH), Homabay Teaching and Referral Hospital, Jaramogi Oginga Odinga Teaching and Referral Hospital (JOOTRH), and Lumumba Sub Country Hospital. KEMRI's Clinical Research Center (CRC) was used as an additional interview site as needed (Kenya Medical Research Institute, 2019)

Study population. Participants comprised 3 strata across selected health facilities: APHIV (n=14), caregivers to APHIV (n=15), and healthcare providers of ALHIV (n=16). Eligibility criteria for APHIV included being 11-19 years of age, aware of HIV status, currently receiving ART, having a documented perinatal infection, and having a caregiver also willing to participate in the study. APHIV were excluded on the basis of not giving assent, unwillingness of caregivers to provide informed consent, and inability to attend their study appointment. One potential participant was excluded due to diminished capacity to provide consent because of a mental condition. Caregivers and providers were purposively sampled from those directly involved in the support and care of participating APHIV (Kenya Medical Research Institute, 2019).

Recruitment. The KEMRI team purposively sampled a subset of the APHIV sample recruited for the quantitative component of their study for the qualitative portion, which was used for this paper. For the quantitative sample, potential APHIV were randomly selected at weekly peer support groups. After confirming age and mode of HIV acquisition through reviewing patient records, APHIV were then invited to a screening visit. Those who continued to meet eligibility criteria were asked to attend an enrollment visit, where consent/assent, locator information (i.e., mobile phone numbers, addresses, emergency contact information, etc.), demographic information, and samples for the clinical examination were obtained. At the enrollment visit, a subset of APHIV were asked to participate in interviews and focus group discussions (FGDs). Participation in both interviews and FGDs was on a voluntary basis. From the 133 APHIV sampled for the quantitative portion, 14 APHIV were recruited for interviews. Approximately 8 APHIV participated in each of 2 male FGDs and 3 female FGDs (Kenya Medical Research Institute, 2019).

Caregivers were purposively sampled from each study site via quota sampling to ensure participation from each study facility. Eligibility criteria included being directly involved in the care of an APHIV. Two caregiver FGDs were conducted, with approximately 8 participants each. Providers were similarly recruited purposively to ensure distribution across health facilities. Quota sampling was additionally used to recruit from the following categories: providers (n=5), healthcare workers (n=4), peer educators (n=7). Healthcare workers included nurses and adherence counselors. The sample size for each stratum allowed for saturation on a broad research topic for a relatively homogeneous sample population.

Data collection. All data were collected by KEMRI between July 2019 and August 2021. The Emory team was invited to participate in data analysis by KEMRI. Quantitative data consists of demographic and clinical surveys, including information on age, age of disclosure, and ethnicity. The qualitative data consists of de-identified transcripts of interviews with APHIV, caregivers, and providers, as well as de-identified transcripts of FGDs with APHIV and caregivers.

Quantitative data were used to describe the characteristics of participants. Each participant was assigned unique ID numbers by KEMRI. For APHIV participants, these ID numbers were used to link survey data to the interview transcripts.

Interviews and FGDs were led by experienced researchers using semi-structured guides. The interview and FGD guides focused on the lived experiences of APHIV, asking questions about barriers to and facilitators of adherence, experiences with clinic attendance, school and home environment, social relationships, and mental wellbeing. Guides were inductively adjusted partway through the study to include additional questions about sexual relationships.

Interviews and focus groups were conducted in the preferred language of participants (English, Luo, Swahili, or a combination) and at a comfortable/neutral location to allow participants to express themselves freely. Interviews lasted approximately 60-90 minutes. FGDs for APHIV and caregivers were stratified by gender and each lasted roughly 90 minutes. Data were recorded via audio recordings and note taking.

Data Analysis. Data recordings were transcribed verbatim and data collected in Swahili or Luo were translated into English. A second staff member assessed 10% of the transcripts against the digital recordings for quality assurance (Kenya Medical Research Institute, 2019).

Codes were developed both deductively, based on a comprehensive literature review and study research priorities, and inductively after piloting the transcripts and noting emerging themes. Four transcripts (1 ALHIV interview, 1 ALHIV focus group, 1 caregiver interview, and 1 provider interview) were piloted using the preliminary codebook and adjustments were made. All transcripts were reviewed by two researchers to establish inter-coder reliability.

Descriptive statistics were generated from the quantitative data using SAS software version 9.2 (SAS Institute Inc., 2009). Qualitative data were analyzed with MAXQDA Plus 2022 (VERBI Software, 2021) using thematic analysis and the constant comparison method, with stratification based on age, gender, location, and disclosure experience. Findings were conceptualized using a grounded theory approach through the lens of the SEM. Data were validated using the concept-indicator model, testing alternative theories, and iteratively returning to the data, including use of memos. Researchers practiced reflexivity during analysis through memos and journaling.

Ethical approval. As our study comprised the secondary analysis of existing, deidentified data from KEMRI, no IRB approval beyond that secured by KEMRI for original data collection was necessary.

3. 4 Results.

The majority of APHIV interview participants were female (n=10), with a mean age of 15 years, and age range of 13 to 19. All APHIV reported their ethnicity as Luo, and the majority reported their religion as Protestant or Other Christian (n=10). APHIV utilized KCH (n=6), JOOTRH (n=4), Homabay (n=1), Lumumba (n=2) and CRC (n=1) as care facilities. On average, APHIV were aged seven years at disclosure, with six reporting disclosure within the WHO recommended age range of seven to twelve years. The majority of APHIV (n=8) were classified at WHO HIV stage 3.

Variables	**Frequency (n=14)**
Demographics of APHIV Interview Participants	
Gender	
Male	3
Female	10
Don't Know	1
Age	**Average = 15**
Young Adolescence (11-14)	7
Older Adolescence (15-19)	6
Don't Know	1
Ethnicity	
Luo	13
Don't Know	1
Religion	
Protestant or Other Christian	10
Roman Catholic	2
Muslim	1
Don't Know	1
Local Healthcare Facility	
KCH	6
JOOTRH	4
Homabay	1
Lumumba	2
CRC	1
Age at Disclosure	**Average = 7**
0-6	5
7-12	6
13-15	2
Don't Know	1
WHO Stage (n=14)	
1	5
2	1
3	8

A wide range of relationships play diverse and sometimes oppositional roles in APHIV engagement in care. These relationships include sexual or romantic partners; caregivers, siblings, and other relatives; peers and friends; teachers and other school staff; and other ALHIV. Findings are structured with reference to Bronfenbrenner's SEM, with overlap between levels due to the reciprocal nature of interactions. No chronosystem factors were found.

Individual

Across strata, participants cited self-stigma[1], or the fear of being stigmatized, as a main factor dictating APHIV engagement strategies. Many APHIV described strategies to avoid self-stigma by maintaining secrecy, such as storing ART in bags to make less noise, giving ART medications to school nurses or matrons so their peers would not find them at boarding schools, or, for APHIV in day school, taking ART at home. Some APHIV shared that they either have only dated or plan to only date other ALHIV to avoid the stress of disclosure and potential negative consequences. APHIV also described "testing" their friends and partners to see how they would react to their status prior to disclosing to them, including asking about hypothetical situations or telling them about a fictional person with HIV to see how they would react.

Some APHIV shared that they set alarms or keep time through radio, TV, or other means so that they know when to take their medications. However, many APHIV, across demographic characteristics, shared that remembering to adhere or feeling able to adhere on time was a challenge. Most APHIV, at one point or another, shared that they threw away or hid their ART for some period of time due to confusion as to why they were taking drugs, poor mental health, or to avoid accidental disclosure.

Microsystem

Autonomy. A common theme that arose is that APHIV require additional support compared to during their childhood, despite many caregivers perceiving them to require less

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[1] Self-stigma was the phrasing used by participants. However, in literature, the same concept is referred to as anticipated stigma

support once reaching adolescence. APHIV and providers cited reasons for needing increased support as new challenges relating to school schedules, romantic and/or sexual relationships, and peer pressure. Many caregivers, APHIV, and providers shared that caregivers commonly believe that APHIV are more mature and should not need someone to monitor their adherence, which can lead to caregivers becoming less involved over time. While the level of caregiver support depends on the specific APHIV, level of disclosure, emotional stability, and many other external factors, providers and APHIV agreed that all caregivers should somehow be involved in supporting APHIV. Some caregivers seek a balance between APHIV autonomy and caregiver involvement. For example, some APHIV shared that their caregivers test them to see if they will remember on their own, which makes them want to prove that they can remember. Although providers expressed that some APHIV are responsible enough to monitor their own adherence, most participants, across demographic characteristics, expressed that lack of caregiver involvement causes APHIV to not take their treatment seriously or become forgetful.

> *"I was willing, but I was not consistent, and I would take [ART] one day then forget the next day." – Male APHIV, age 12, Lumumba*

All providers reported that, in their experience, parents are more likely to be involved than guardians, which makes it difficult to coordinate care with guardians, who have expressed to providers that they do not feel capable of supporting APHIV since they do not have HIV. Some APHIV worry that guardians love them less than their biological parents would. However, providers noted that having a guardian for APHIV to guide them and assuage potential guilt over their parent(s) dying is important.

> *"With adults, they can make their individual plan on what they want to do or how they want to take their medicine, if they want to take it they will take it, if they don't want to take it well*

> *they will do as they wish, but with adolescents and children they need to be supported by their parents and care givers, they still need support and they need to be guided" – Health Care Provider, Homabay*

Disclosure status. The directionality of support from romantic or sexual partners depends heavily on whether they have been disclosed to. Disclosing to others is an important step in building close relationships that support APHIV engagement in care. APHIV shared, through actual experiences of disclosure or discussing hypotheticals, that disclosing can allow others to provide direct engagement support, emotional encouragement, and/or an opportunity for APHIV to share their experiences. Conversely, not disclosing, particularly to friends or partners, may negatively influence adherence by causing APHIV to skip ART doses when in their company to avoid accidental disclosure.

APHIV have many fears about disclosing to others, including that their romantic or sexual partners will break up with them or friends will abandon them, they will be treated poorly and feel stigmatized, and/or that their status will be told to others, leading to isolation and discrimination. There were some slight gender differences in disclosure-based fears regarding partners, with multiple female APHIV afraid that their boyfriends' negative reactions would make them want to die, while male APHIV largely feared transmitting HIV to their girlfriends. Some APHIV validated these fears by sharing their personal experiences of friends isolating from them or gossiping to others.

Direct Influences. Many participants, across demographic groups, expressed that social relationships directly influence adherence. Many APHIV shared that caregivers, siblings, and other relatives remind them of the time, set alarms for them, and even observe them adhering. Some providers and caregivers noted lack of follow-up on adherence can lead to APHIV skipping ART doses without anyone noticing, or even intentionally delaying adherence to garner attention and concern from caregivers.

> *"Adolescents also are considered by some parents to be people who can now take care of themselves while they are not understood as people who are going through emotional and physical development. The parents may assume the child is taking medication while they are actually not taking medication well." – Health Care Provider, KCH*

The use of food to remind and entice APHIV to adhere has an added benefit of helping APHIV overcome their fear of taking ART due to the side effects. Being given sweets or a favorite fruit after taking ART eases the nausea they feel and also counteracts the bitterness of the drugs. Some caregivers buy APHIV special foods on the way home from the clinic to encourage them to attend clinic visits. Some APHIV shared that their caregivers previously did this during their childhood but stopped once they reached adolescence.

Neglect and abusive relationships with caregivers can also have directly negative influences on APHIV engagement in care. APHIV and providers alike shared that stepmothers are particularly likely to mistreat APHIV and unlikely to attend clinic visits when asked. Some providers noted a common observation that APHIV are not given much food to eat at home. One APHIV gave an example of this, sharing that his stepmother makes him leave dinner early to take ART while the other children without HIV are able to eat more. Providers and APHIV expressed the importance of having enough to eat, since it is difficult for APHIV to adhere on an empty stomach. Some providers shared stories of caregivers using forced disengagement in care as a punishment, such as stepmothers who deny APHIV permission to attend the clinic or force female APHIV to cook all the time, which results in missed doses. Many providers described similar anecdotes of APHIV they have cared for:

"There is nobody to bring on board squarely and say this is the person we want to be a treatment supporter to this child. To me, I just say that these children have been left alone to die." – Peer Educator, Homabay

Mental health. Mental health proved to be a critical intermediary factor influencing APHIV engagement in care. Participants, regardless of demographic characteristics, expressed that poor mental health often culminates in nonadherence and/or refusal to attend clinic visits because APHIV are wanting to die. Multiple APHIV expressed feeling, at some point, alone, fearful of discrimination, and/or like they did not fit in the world. All APHIV, at some point, felt exhausted by the idea of taking medicine for their whole life. These emotions led to either passive disengagement via being forgetful and not invested in adherence, or active disengagement, such as throwing ART away, lying about adherence, and skipping clinic days. The outcomes of poor mental health, as described by APHIV, caregivers, and providers, were that APHIV die by treatment failure or suicide, or APHIV are encouraged to take control of their life, understand that they can live long and healthy lives with HIV, and begin to engage in treatment again. The only support that participants across strata referenced to save APHIV from suicide were social relationships, especially those of caregivers and siblings, who convinced APHIV that they would be okay.

Encouragement. Social relationships that provide encouragement, not just to adhere, but to live, improve APHIV motivation to continue to engage in care. Many participants across demographic characteristics shared that encouragement is especially critical for APHIV who are anxious, depressed, frustrated with the tedium of adherence, or forgetful, all of which hinder adherence. APHIV reported that having people who encourage them to be patient, strong, and courageous is helpful, as is the provision of guidance, advice, and counseling. They additionally shared that being reminded of the benefits of and negative impacts of nonadherence helps them not forget the importance of adhering. Some APHIV shared that caregivers and relatives inform them that ART will make them strong and active, or that if they skip ART, they will have high viral loads, be exposed to diseases, feel faint and weak, or get sick like when they were younger. Some APHIV shared that their caregivers tell them nonadherence will cause symptoms that people will notice and gossip about. In this way, caregivers use the fear of stigma as a tool to urge APHIV to adhere.

Sometimes, well-intentioned encouragement can have a negative impact on engagement in care. Some APHIV and providers shared anecdotes about caregivers without HIV who try to encourage APHIV by caning them for nonadherence, telling them they will die like their mothers, or threatening to throw them out of the house if they skip ART. While one female APHIV reported that she adhered better to avoid quarrelling with her mother, most APHIV interpreted this kind of harshness as a sign that caregivers do not care about their child and expressed that it would make them feel less desire to engage in care, even choosing to stop adherence so as to die. Some caregivers shared that being close to APHIV, talking to them, and learning about their experiences helps them realize what APHIV may find offensive and avoid doing and saying things that may insult APHIV and result in disengagement.

> *"I never used to miss drugs, but my mother also started to encourage by saying that if you take drugs well like this you will be healthy and then you will grow fat, and then I said "but eh! I don't like that issue of becoming fat and so I said to myself, let me reduce it a bit, so I did not take my drugs well for one month and so the viral load also increased." Male APHIV, JOOTRH, FGD*

APHIV described other PLHIV as especially helpful in encouraging them. Many participants across demographic characteristics shared examples of this, including advice from caregivers with HIV based on their own experiences, encouragement not to give up from partners with HIV, and friends with HIV teaching them to be courageous and unafraid of taking drugs. Encouragement can be by example as well, with many APHIV reporting that seeing other healthy PLHIV, especially ALHIV, encourages them to engage in care so that they too can live without symptoms. APHIV shared that knowing and seeing their caregiver(s) take drugs encourages them to adhere better, have a more positive life outlook, and relax. Caregivers with HIV agreed, emphasizing that accepting their own status, taking care of themselves, and taking their own drugs served as an important example to their children.

> *"For me, my child asked me 'mum will I also have a family when I grow up now that I am positive" and I told her yes and nothing will hinder you from having a family because I am also in the same situations…" – Caregiver, female, FGD*

Incentives from support groups and caregivers also motivate APHIV to adhere and attend clinic. Some APHIV shared that support groups in and of themselves function as a reward to help remind them of clinic visits so they do not miss their support group, with some APHIV partially attributing their low viral load to support groups. Some support groups or caregivers provide gifts or competitions for achieving or maintaining viral load suppression, which APHIV and providers said helped adherence and clinic attendance. Gifts given to APHIV included expensive watches, phones, favorite foods, or small parties, which made APHIV feel happy, loved, and eager to adhere. Some APHIV reported that their caregivers stopped doing this once they reached adolescence.

Acceptance of Status. Across demographic characteristics, all participants discussed that an important influence on engagement in care is APHIV's acceptance of their status. Providers noted that this was uniquely challenging for APHIV compared to adolescents with behaviorally acquired HIV. Relationships that make APHIV feel normal, less alone, loved, and cared for help them accept their status and promote willingness to engage in care and, at a basic level, desire to survive. Conversely, feeling alienated, unwanted, unloved, or abnormal can increase APHIV's likelihood to default on medication. Acceptance is often aided by having relationships with other PLHIV, particularly with ALHIV, but knowing someone with HIV is not requisite for this kind of attitude.

Normalcy and not feeling alone. A critical function of social relationships, namely with caregivers, partners, siblings, peers, and peer ALHIV, is helping APHIV feel normal and less alone, which subsequently leads them to feel more willing and able to engage in care. APHIV reported that seeing other healthy ALHIV, including siblings, school peers, and ALHIV in support groups, empowered them to accept their status. Some APHIV shared that having peer ALHIV at school helps make school manageable because they understand their situation better, can provide encouragement, talk to them about challenges, and take medications together. Some APHIV shared that seeing a friend with HIV who is not adhering makes them feel obliged to disclose their own status and help them adhere better. At one school, ALHIV have formed a group to motivate each other, similar to the clinic support groups.

> *"There are others in school who are also taking drugs and we know each other and have even formed our own groups and so you know we are encouraging each other to take drugs so that our viral loads may not rise. The encouragement that we give each other makes us to take the drugs well." – Adolescent, male, JOOTRH, FGD*

Serosorting relationships similarly makes APHIV feel happy that they do not have to deal with everything alone, with all APHIV, regardless of experience, agreeing that this would make them feel loved and normal. While some APHIV felt that having friends and romantic partners without HIV can similarly offer normalcy, many participants, across demographic characteristics, expressed that this sense of desire for normalcy may manifest in nonadherence and skipping clinic visits so that APHIV can ignore their status. Several APHIV shared that being the only one of their friends with HIV made them feel bad, so they stopped adhering in order to better relate to their friends.

Regardless of demographic differences, all participants expressed that support groups are uniquely capable of helping APHIV feel normal, comfortable, relaxed, encouraged to adhere, and less alone by allowing them to socialize with peers who are living healthily with HIV. Some APHIV shared that support groups helped them accept that they must be fully engaged in treatment and that there is no backing out. The sheer number of ALHIV in the clinic additionally helps APHIV to stop questioning their status and eases anxieties through the knowledge that other ALHIV have gotten used to adhering and are healthy.

> *"We're put in a group with other children where we were taught, we played in the playground and while playing you feel comfortable because you are not alone." –Female APHIV, age 12, KCH*

Providers noted that APHIV generally tend to be more withdrawn during support groups than adolescents with behaviorally acquired HIV, although this is not always the case. One mother shared that her daughter teaches younger ALHIV because she is so well-spoken. Being amongst other ALHIV in support groups can mitigate risks of clinic disclosure by helping APHIV understand their status better and immediately demonstrating that they are not alone. When asked about disclosure recommendations, many APHIV suggested that children be brought to support groups immediately after disclosure.

> *"What I can say is that there are some teenagers who are weak at some points and that can make them commit suicide things that God does not accept so they can be placed in a group like ours here and they talk." – Female APHIV, Homabay, FGD*

Clinic-organized outings further normalize APHIV by allowing socialization with a larger range of ALHIV to validate experiences. These contrast with school outings, where many APHIV admitted skipping ART due to forgetfulness or because they were uncomfortable taking their medication around peers. Many caregivers do not allow APHIV to attend school outings in order to avoid poor adherence. However, some caregivers expressed that, as high schoolers, APHIV are more independent and should be allowed to go. A few caregivers reported that they compensate for not allowing APHIV to attend school outings by taking them on family trips to help them feel normal and maintain adherence. Clinic-organized outings similarly provide a balance of helping APHIV feel normal and relaxed as well as motivated to adhere and, as some caregivers perceived, hopeful for their futures.

Peer pressure. All participants named peer pressure as a main challenge for engagement in care, which can take the form of socializing more and forgetting to adhere, actively disengaging to avoid accidental disclosure, or being told by peers not to adhere. Across demographic differences, some APHIV shared that they stopped ART as soon as their peers suspected their status. Similarly, some providers shared that APHIV skip clinic visits to see friends instead. Some providers shared that older ALHIV often ask if they can stop treatment until they are finished with school to avoid being insulted by their peers or they tell providers that they already had stopped ART in high school to avoid peer discrimination. Many providers classified fear of peer discrimination as an example of self-stigma. Providers and APHIV echoed the sentiment that APHIV want to be able to feel like their peers without HIV, and being unable to do so can make them feel lonely, isolated, depressed, and more likely to stop adhering.

> *"I had a 3 year break from taking the drugs. I would take them sometimes but not punctually. I had to be transferred to a day school because of how often I was unwell and because I didn't want to be seen taking medication in the sickbay. Even if you carry them, they have an odor. So I couldn't take them even when I'm with my friends. I used to take them once in a while but it was three years." – Female APHIV, age 17, JOOTRH*

Some APHIV shared examples of feeling pressured by peers to disengage, such as being told that they are being deceived and do not need to take medication, that if they leave the friend group to take ART they will not be welcomed back, or being mocked, laughed at, and teased when they take medication at school.

> *"At times their friends encourage them to stop taking drugs and they will benefit afterwards. They feel like nothing will happen to them if they stop taking them." – Female APHIV, age 12, KCH*

Some female APHIV reported positive experiences with disclosing to friends without HIV who treated them normally and encouraged them to adhere at school and on school outings. One caregiver uniquely shared that her daughter has a friend without HIV who accompanies her to the clinic. Only one male APHIV reported feeling supported by a friend, although the friend did not know the drugs he was taking were for HIV. Another male APHIV noted that his cousin who attended school with him positively influenced his adherence by helping hide his ART from peers who were looking to confirm his status.

Several providers expressed that an important caregiver role in fostering normalcy is ensuring that APHIV know they are not special, which helps APHIV feel free to live autonomously, like their peers, instead of feeling like their life is dictated by their status. Conversely, some caregivers felt that prioritizing the needs of APHIV over other children prevents APHIV from feeling bad and helps imbue trust in the caregiver.

Many APHIV expressed that living with family who have HIV and being able to take ART together helps exemplify how adherence keeps them healthy and makes them feel that adherence is normal and necessary. Some caregivers have even changed their own time for taking ART so that they could take ART together with their child. This effect is amplified for APHIV with both parents and siblings with HIV because they do not see anything different, which makes them feel less alone and more capable of adhering as a normal part of life. APHIV with family who do not have HIV, at some point in their lives, have questioned why they alone take medication.

> *"One who asked why was he taking drugs in the family alone because everyone in the family, mother, father, siblings were negative, now he used to ask until it reached a point he refused to take his medication and almost died but he was helped." – Health Care Worker, JOOTRH*

Feeling loved and cared for. Close relationships that provide love, affection, and care improve APHIV morale and promote their desire to adhere, suppress their viral load, and live. Many APHIV implicitly or explicitly correlated feeling loved with feeling supported in treatment. While all APHIV expressed feeling encouraged in some way, male APHIV reported fewer instances of this kind of emotional support from caregivers and friends than female APHIV. Having multiple sources of love and support is important, as some APHIV shared that they feel more comfortable talking with relatives or friends than caregivers about certain topics.

"I asked why me and not others and so I felt that it was better if I committed suicide but I did not tell my father that I wanted to kill myself but I only shared with my brother who encouraged to take my drugs." – Male APHIV, JOOTRH, FGD

It is further useful to have relatives able to help APHIV feel loved when they visit their rural home[2], as well as siblings to encourage APHIV when caregivers are away from home, to help combat negative mental health and improve their will to survive.

"I felt alone, I despised myself, and it reached a point when my sister told me, "Take these drugs, we don't want to lose you." – Female APHIV, JOOTRH, FGD

Romantic partners who provide love help APHIV relate to their peers without HIV and reduce a common discouraging fear about not being able to find someone to love them. Caring for a partner without HIV can also increase APHIV's engagement to protect their partner against HIV transmission. However, providers emphasized that sometimes APHIV's desire to feel loved and relate to their agemates can lead to disengagement from care in order to maintain secrecy.

Caregivers are especially important in making APHIV feel loved and cared for. APHIV reported feeling motivated to adhere when their caregivers: expressed that they wanted them to grow well and succeed in careers, future, and life; expressed other words of affirmation; gave them informational books; took APHIV on special trips; or took them to church. Many participants, across demographic differences, emphasized that feeling loved helps APHIV overcome common mental health challenges. Some caregivers expressed the importance of being a friend, not enemy, to the APHIV while others emphasized that caregivers should provide companionship for their children.

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[2] The rural home refers to APHIV's household in a village, where their grandparents, aunts, uncles, and cousins live. Adolescents in Kenya often visit their rural home over school holidays.

Caregivers who cannot support their child's treatment, either because they are busy at work or believe APHIV can support themselves, can make APHIV feel neglected and uncared for, resulting in APHIV giving up and disengaging from care. Taking medication together provides a time for caregivers to talk with and encourage APHIV, remind them of the importance of adhering, and gauge their understanding and gradually disclose. Some caregivers tell fun stories for APHIV to positively associate with adherence. When asked what caregivers should do to help APHIV, one participant shared:

"Giving them advice, making stories, and just keeping them close" - Female APHIV, age 18, Homabay

Providers reported that depression is common among APHIV who do not feel supported by their caregiver. Similarly, many caregivers believe that being too harsh with APHIV, including quarreling often with them, can negatively impact their mental health by making them feel uncared for. One female APHIV was pregnant and shared that she often quarreled with her caregiver about the pregnancy, which resulted in her avoiding meals just to avoid her aunt, and ultimately taking ART without food and amplified side-effects she felt from the medication. Some caregivers suggested the importance of practicing empathy to avoid giving APHIV undue stress, which hinders their willingness to engage in treatment.

"Maybe we have caregivers who sometimes are not supportive and who may tell the adolescent "I am tired of you, you know that you are taking your medication and you are asking me for permission to go, if you want to die, die." They don't create environment which is friendly to the adolescent. That one can make them to default" – Peer Educator, Homabay

Lack of involvement can also occur through willful neglect or abuse, which subsequently causes APHIV to disengage from care. Participants described neglectful caregivers as failing to follow-up on adherence out of a lack of care for the APHIV, because the APHIV has no committed primary caregiver, or because caregivers lack an understanding of HIV treatment. Some APHIV and caregivers reported that a parent was negligent or irresponsible with the APHIV as children, sometimes resulting in the death of a sibling from HIV, so an aunt, older sister, grandmother, or neighbor became their primary caregiver. Some APHIV shared secondhand stories of APHIV being told by caregivers without HIV to deal with their own situation and refusing to attend clinic visits of APHIV failing treatment, even when asked by the provider. Many APHIV interpreted caregivers' failure to support APHIV as the result of not being educated about HIV, not caring enough about the APHIV, or a combination of the two.

> *"My father is someone who doesn't know anything, he is also negative. Even now that we were told to come…it's like he is not educated on this medication. So I found it hard. No one cared, everybody is just like, "Yes take the drugs." but no one sit you down and talk to you well. So it was tough" -Female APHIV, JOOTRH, FGD*

Age of disclosure. Many providers believe that the number one challenge for engagement in care is lack of or delayed disclosure. Numerous caregivers and providers alike suggested that delayed disclosure can cause mental disturbances and lead APHIV to stop treatment, arguing that disclosing at an early age helps APHIV understand their condition, stop questioning why they take drugs, and better remember to adhere. Participants across demographic characteristics discussed how disclosure is an important influence on how APHIV learn to manage their health and handle challenges.

Delayed disclosure reduces the likelihood that ALHIV accept their status, which can have serious mental health consequences leading to treatment failure. Some caregivers wait for APHIV's brains to mature before disclosing, arguing that APHIV may share their status with friends if they are told before they are able to fully understand. A number of APHIV agreed that disclosing when a child cannot understand risks those children's suicides. Some caregivers, APHIV, and providers shared that caregivers sometimes tell lies about being able to stop medication when they are older or healthier in order to encourage APHIV to adhere before they disclose to them. While one provider thought that lies can help ease adherence challenges for children and younger APHIV, most expressed that this has a negative impact on engagement in care because it makes disclosure more shocking and harder to accept. This sometimes leads to nonadherence when APHIV feel like their life is already over. Providers perceived that APHIV disclosed to in adolescence are often bitter and rebellious because they blame their parents and thus struggle to accept their status, thus emphasizing the importance of early disclosure. Many APHIV felt that each APHIV is very different, so the best age for disclosure varies and should be left to the discretion of their caregiver.

> *"You find that when a child is disclosed to his/ her status at a late age they will resist. He/ she will not adhere to medication that is why we always insist that the care givers start their disclosure as early as 6 years so that when it reaches 10-11 years the disclosure process is over. If the disclosure is done late the child stops medication why they were not told early, mum has just been lying to me that I have a chest problem." – Peer Educator, Lumumba*

Numerous APHIV and caregivers expressed that APHIV understand and come to terms with their status better when disclosure comes from parents. Some caregivers and providers reported that parental disclosure reduces the likelihood of APHIV blaming their parents, which often leads to poor adherence since APHIV feel it is not their fault nor responsibility that they need medication. Other relatives sometimes step in and disclose if caregivers are not home when APHIV ask questions about their status, or if the caregiver refuses to disclose. One female

APHIV shared that her sister disclosed to her since the mother did not believe she was old enough, even though she had stopped adhering.

Many providers suggested that delayed disclosure is common for: parents living with HIV who feel guilt over their child's status; caregivers living without HIV who do not feel competent about HIV; and caregivers who feel that it is not their place to disclose since the parents did not and they are unsure of the APHIV's reaction. However, all APHIV and providers were consistent in the belief that caregivers should be responsible for disclosure. Providers pointed out that the law prevents providers from disclosing alone and that caregivers help APHIV better understand their status. Many providers suggested assisted disclosure, where caregivers disclose at the clinic with a provider present, as a strategy to mitigate insufficient or misinformed disclosure.

"He/she may have acquired HIV perinatally, but the notion that comes out is that HIV was acquired through blood transfusion. This adolescent grows thinking that the parents are not on care." – Health Care Worker, JOOTRH

Delayed disclosure also increases chances of accidental disclosure, whereby APHIV or someone close to them notices parallels between the APHIV and other PLHIV, such that they piece together that they have HIV. One female APHIV's caregiver never disclosed, but after a period of time, the adolescent came to know and accept her status and is now doing well on treatment. However, this seems to be the exception, with some providers and APHIV sharing secondhand stories of APHIV experiencing accidental disclosure and refusing treatment. Late disclosure also means that APHIV cannot take full advantage of the important help that support groups offer.

"For disclosure of adolescents, we expect that when they reach 10 years, disclosure should be fully done, but to some of the adolescents you find that they have attained 10 years, yet no

> *disclosure is done… The caregivers normally delay with disclosure issues and as a result you find that some of the adolescents when they come to know their status later, they start defaulting which may probably result to high viral load." – Peer Educator, KCH*

Method of disclosure. Despite differences in opinion on the best age for disclosure, all APHIV agreed that they should not be left alone following disclosure, with several APHIV addressing the impact of disclosure on suicide ideation and attempts from personal, secondhand, and hypothetical situations. Siblings present during disclosure, even if they themselves do not have HIV, can help APHIV calm down, provide comfort, and help APHIV accept their status.

> *"Like for my case after knowing my status I had bad thoughts in mind I said that I will take poison and die. If I would have been left alone for a while I would have taken poison." – Female APHIV, age 14, Lumumba*

Two female APHIV shared that if their parents had not been the ones to disclose to them or if they had been left alone immediately following disclosure, they would have attempted suicide. This almost became a reality for two other APHIV, both of whom were disclosed to at the clinic. One female APHIV immediately went home and attempted suicide when her mother caught her. The APHIV shared that she could not talk, but cried as her mom took the rope away, talked to her, and gave her a Bible to read. Another male ALHIV made a suicide plan before his father, who also lives with HIV, talked to him and explained that he can live healthily with HIV.

> *"So by that time I felt like the world was so small, the world was so small and I did not know what to do. I felt like there was nothing to look up to" – Male APHIV, JOOTRH, FGD*

Mesosystem

Encouragement from relatives, friends, and caregivers can help mitigate negative social interactions, including stigma-related discrimination, and encourage APHIV adherence. One

APHIV shared that when she felt HIV-related discrimination and stress, she visited her grandmother, who encouraged her to continue adhering. Sometimes, caregivers and other relatives talk to those who are discriminating against APHIV to explain their situation and educate them about HIV, which can help reduce stigma and increase support. One male APHIV shared that his sister's husband discriminated against him until the sister spoke to him, after which point he was kinder and even transported the APHIV to the clinic sometimes. Caregivers in particular play an important role in encouraging other family members not to discriminate and instead provide love and care to APHIV.

Caregivers influence on other relationships. Caregivers also have a pervasive influence over how APHIV conduct relationships with others, especially peers who suspect they are taking drugs, romantic or sexual partners, relatives who they have not disclosed to, and school staff. A significant aspect of this influence is whether caregivers disclose to others for APHIV or who they tell APHIV to disclose to. Some caregivers tell APHIV that their status is a family secret or that if they disclose to anyone, others will talk about it or not want to play with them, it will put them at risk, or it will cause distractions that will interfere with their education. In this way, caregivers' perspectives play a significant role in how APHIV learn to interact with others with regards to their status, as they transition into adolescence.

Caregivers and biological parents. When guardians take over primary care of APHIV, the guardian and APHIV sometimes still maintain relationships with the biological parent. This often occurs when a neighbor or relative notices the neglect of an APHIV by their parent, particularly parents who are unaware of or have not accepted their own status, or who are alcoholics, whereby the new caregiver becomes an advocate for the APHIV, then gradually takes over primary care.

> *"My mother died when I was young and I was staying with my father…my father was not taking part in his responsibility well and even lost my older sister. So my mother's sister took me to stay with her." Female APHIV, age 14, Lumumba*

The process of taking over care requires negotiation between the incoming caregiver and the biological parent(s). One caregiver shared that she takes in APHIV in her community who are not being cared for by their parents, including convincing parents to allow her to take them for testing, promoting their adherence, and allowing them to stay in her household.

> *"There are so many adolescents who suffer, the mother died they are in a small house and the house is so full I think the first born is 13 years and he is the one fending for the others and they are all on care. I do field work sometimes when I pass there I find this child has not gone to school , he looking for firewood, I know the time they take drugs, I just do pass by to check if they have taken drugs, at times the drugs are lost the house is just in mess, a house without mother, the father is a drunkard and still a young person., and gets to the house at 10:00 pm so it breaks my heart so much." – Caregiver, JOOTRH*

Caregivers and relatives. Siblings and other relatives are critical substitutes for supporting adherence when caregivers are away. Some caregivers leave instructions for their other children to help remind APHIV to adhere when the caregiver is away. Being able to rely on siblings and other relatives helps mitigate lack of involvement of caregivers who work late or travel often for work. Similarly, across demographic characteristics, all participants shared that the involvement of school staff, including teachers, matrons, nurses, principals, and school officers can help support adherence while APHIV are away from home, particularly those in boarding schools.

Caregivers & Teachers. Caregivers influence how APHIV navigate HIV-related challenges at school. Many providers encourage caregivers to disclose to school staff for their children, especially when starting high school and/or boarding school – when many APHIV stop taking drugs – to help APHIV adhere and have permission for clinic visits. This can help resolve adherence barriers such as not being allowed to bring water to class or being able to leave class to take ART. Some APHIV pointed out that their caregivers only disclosed to teachers when they were younger and stopped during high school. In some instances, lack of disclosure by caregivers was a deliberate attempt to protect APHIV from teachers' discrimination. However, disclosing to teachers allows caregivers to rely on them for adherence follow-up at school. This is especially true for APHIV who shared that they do not have enough time in the morning to take ART, vomit if they take it too early, or may try to avoid ART by pretending to be too busy in the mornings.

> *"There are times when I go to sleep am woken up to take my dose so I cover myself when I go to sleep so that when am called I pretend am asleep so that I take the next day and if I go to school the next day I pretend to be busy and leave not knowing my mother has packed for me my drugs and tea when I go to school I have to take them because the teacher is watching me." – Female APHIV, age 13, KCH*

Communication between caregivers and teachers additionally helps APHIV to feel normal and less alone in school, which helps improve adherence. While some teachers who have been disclosed to tell other peers about the APHIV's status, making APHIV feel powerless against the stigma, some caregivers and APHIV shared that teachers who are disclosed to and are helped to understand their status can help APHIV meet peers with HIV so that they can be friends, which helps reduce the pain of other peers isolating from them and discriminating against them. Many caregivers believe that there should be more support in school to help those who need it, including that teachers should speak up if APHIV are being discriminated against by peers.

> *"They ought to speak out to a teacher when he is being discriminated against or being abused by other students. I also took initiative of going to the teachers and telling them about my child's status so that they know how to handle him." – Caregiver, Homabay*

Caregivers and Peers. Providers shared that it is important for caregivers to be aware of who their child is befriending, suggesting that otherwise caregivers will not notice APHIV having friends who may negatively impact adherence. Caregivers may also be able to identify other APHIV at school or in the community so that youth can have friends who share similar experiences and can support each other. Lastly, while many caregivers refuse to let APHIV go to camps, sports, or other activities where caregivers cannot monitor adherence, some encourage APHIV to participate so that they feel the freedom of being healthy, normal, and at peace.

Caregivers and Providers. Providers emphasized that caregivers are vital in supporting treatment at home through communicating with providers. All providers agreed that it is particularly important for caregivers to attend clinic visits when APHIV are failing treatment to fill in knowledge gaps for providers so that they can provide relevant counseling and link ALHIV with appropriate support services. This includes information that APHIV may refuse to share or, as teenagers, may not feel open enough to share, such as adherence challenges or refusal to adhere, thus better preparing providers to support adherence. Caregivers also tend to ask questions of providers which APHIV may be less likely to ask themselves, and this helps APHIV learn more. Having caregivers advocate for their child is useful when APHIV experience side effects of ART or have trouble with the large number or size of them, because it helps providers know to change their ART so that APHIV are more willing to adhere. Some providers also noted that caregivers are more likely to notice and correct when pharmacies accidentally give the child the wrong type of ART.

> *"We use both the adolescent and the caregiver in the event that the caregiver comes because sometimes when we hear one side of the story we don't get the true picture at home so we use both when they are at the clinic. So sometimes when the clinician or the nurse or the social worker is seeing the patient we can have a session where we have both in the room or we have one in the room so that at least we can hear from both." – Health Care Worker, JOOTRH*

Caregivers also influence how APHIV engage with providers during clinic visits. While all providers agreed that having caregivers come to clinic visits is essential when APHIV are failing treatment, most providers preferred that APHIV who were not failing treatment come to their clinic visits alone, since there are certain topics they may not feel comfortable sharing with their caregiver there, such as poor adherence, for fear of punishment. Providers shared that they talk to caregivers later in private to maintain APHIV's trust while keeping open communication with the caregivers. Caregivers who insist on staying can constrain the quality of care providers are able to give.

A few female caregivers, living with and without HIV, shared that they started counseling for themselves and their child very early so that they knew how to teach APHIV the importance of adherence and independence. These mothers kept quiet during sessions to allow APHIV to participate more. Counseling helped caregivers learn how to give courage to their children and strengthen their own resolve in caring for their children. Some facilities ensure that APHIV and caregivers living with HIV attend the same clinic days so that it is easier for caregivers to attend the APHIV's session if needed.

Exosystem

All participants, regardless of demographic differences, shared the belief that social environment is one of the main challenges for APHIV engagement in care. This includes interactions between caregivers. A unique adherence challenge that a few providers and caregivers identified was violence and disputes between caregivers that they felt harmed the child's mental health.

> *"We have what we call domestic misunderstanding or violence. So domestic violence you find the adolescent have both parents or have the guardian who easily fight. So every time they fight. This adolescent is not able to find one, a room or environment to take their medication so you find some medications are thrown out or burnt. So that is another challenge that they face" – Health Care Worker, JOOTRH*

Rural home. Social relationships are additionally helpful in mitigating changes in environment to help APHIV stay engaged in care, particularly over school holidays. All participants discussed that a common adherence challenge is visiting the APHIV's rural home where many APHIV feel that they have no option but to stop taking ART to avoid accidental disclosure and the fear of being stigmatized or having their status spread by their relatives. APHIV who visit their rural home also struggle with poor nutrition because they are often only fed porridge, and sometimes have limited access to water to take their drugs with. These APHIV described visiting relatives as synonymous with a "drug holiday," whereby they stop taking ART entirely. This is exacerbated if no one in the household is on ART because APHIV are more afraid of being caught, which can result in more missed doses. Many participants shared that APHIV viral loads increase substantially over school holidays because of this.

"They will make it difficult for me to take the drugs and I would sometimes skip them so that they can see I don't actually take the drugs everyday especially when I am with them. So this can make me skip taking the drugs." – Female APHIV, age 17, JOOTRH

Many APHIV and caregivers noted that some caregivers do not allow APHIV to visit family who have not been disclosed to because there is no one there to remind APHIV to adhere. Other caregivers allow APHIV to visit only if the caregiver is also present to ensure adherence. Having relatives who have been disclosed to and/or who have HIV make APHIV more comfortable adhering in their rural home as well as improve their adherence by prioritizing their nutrition. Both APHIV and caregivers shared that aunts are especially helpful in promoting adherence when caregivers are away. Relatives and caregivers who are also able to escort APHIV to the clinic or pay the fare for them to go when they are at the rural home help clinic attendance, because, as many providers shared, rurality can mean limited clinic attendance when family cannot support them in this way.

Support groups. Support groups provide a way for APHIV to connect with and learn from other ALHIV, which providers mentioned is a common concern of APHIV brought up during visits. Some APHIV shared that they recognized peers at the clinic from school and their communities that they did not realize shared their status, and this allows them to become friends and provide emotional support and encouragement outside of the clinic. Similarly, some APHIV look for romantic and sexual partners in support groups to avoid the stress of disclosure.

Support groups additionally allow APHIV to learn from each other about proper adherence, diet, and navigating disclosure and other social relationships. This improves APHIV autonomy by helping them make informed choices about their treatment. Support groups that mix both older and younger APHIV help younger APHIV learn from older ones, who have persisted through similar challenges. Some caregivers indicated that this is particularly important for those who are shy and uncomfortable sharing their own problems because they can still identify solutions by listening to others. Providers at KCH utilize peer ambassadors, who are older ALHIV adhering well and can help teach younger APHIV strategies to overcome adherence barriers. Similarly, some providers use support groups and/or peer educators to help ease disclosure for APHIV. Some caregivers shared that the education support groups provided to APHIV aided caregivers by minimizing the reaction APHIV had during disclosure. Support groups also helped improve APHIV adherence so that they relied less on caregivers for support.

> *"They [ALHIV] know the challenges; they have also undergone some kind of experiences that can help this person who have newly been diagnosed. Therefore, we have tried to use somebody who is already in their shoe, who understand exactly what they are going through. Then at the same time, even those who are infected they tend to give their life experience to the newly diagnosed. It is just living positively that will help them out."* – Health Care Worker, JOOTRH

School environment. Numerous providers noted that many APHIV did not struggle with adherence until starting high school. Participants across demographic characteristics noted that high school is challenging due to recognition that their peers are not taking medications, the school schedule, lacking privacy at school, especially for those at boarding school. The school environment and policy can also influence how APHIV interact with school staff, leading to challenges engaging in care. Some APHIV as well as providers voiced that being seen going to the nurse can raise questions amongst APHIV's peers and sometimes result in nonadherence to maintain secrecy.

Changes in school environments due to relocation, the natural progression between primary and secondary school, or the transition between day school to boarding school pose additional challenges. Each school comprises a new system of relationships for APHIV to navigate and learn how to manage their HIV within. This often results in gaps in adherence while APHIV orient their HIV management, learn to adhere within these new environments, and identify who they can trust and rely on for support. Some caregivers and APHIV noted that gaining support from teachers is particularly difficult when the APHIV changes teachers if the teacher moves or the APHIV goes to a new classroom.

> *"The rules and policies in schools also varied you realize that sometimes the adolescents don't want medication maybe it is that for morning and evening medication they are not allowed to go to the dormitory at particular times so you find that the child will get disorientated how do they manage their taking medication to some school" – Health Care Provider, KCH*

Some providers believed that the government should provide better teacher training, especially about confidentiality. One provider shared an example of an APHIV who was failing treatment, but after assigning a teacher to talk to her and take care of her, she now attends appointments and has better adherence.

> *"When they are in school adherence is very poor because of stigma, they don't want to open up to other students even to the teachers but of late we have gotten a solution because most of our schools around the teachers have been given literacy now they are supporting them but that is a main challenge in boarding schools" – Health Care Provider, Homabay*

The way HIV is taught in school is also influential on engagement in care. Some APHIV's teachers teach that HIV kills or is a curse, causing APHIV to lose hope and believe they would die. Some caregivers shared that being taught about HIV in the classroom raises questions amongst APHIV that force caregivers to disclose. However, one caregiver shared that they delayed disclosure to their child because they worried the APHIV would feel unwanted and would not adhere because of the negative nature of what is being taught about HIV at school. Despite the curriculum, some APHIV reported that their teachers gave good lessons that they felt reduced stigma, such as explaining common myths about HIV. Some APHIV also specified that having peers with HIV at school is particularly important when they are taught in class about HIV.

Some APHIV believed that teachers should be trained on HIV, even suggesting that APHIV themselves train teachers to speak more positively and sensitively about HIV. Providers shared that at some schools, staff are trained on managing students with HIV, with some having a designated staff member to look out for the student. Providers emphasized that designated staff should either have HIV themselves or be trained on how to handle these students' situations appropriately.

"I think we need to blame the teachers when we talk about HIV because they don't teach it well because a teacher will just come and teach that HIV is bad, avoid HIV and sometimes when your colleague learns that you have HIV, they will think that maybe you are dying next year or next month and things like that and that you might infect him." – Male APHIV, JOOTRH, FGD

Macrosystem

All participants shared the belief that cultural stigma around HIV, and consequent self-stigma, is one of the main challenges for APHIV engagement in care. APHIV reported feeling stigmatized by relatives, siblings, peers, and teachers. Stigma presents in numerous ways, including people avoiding touching APHIV, not wanting to play with them or share things with them, teasing or insulting them, telling them to stop taking drugs because they are as good as dead, or scoffing and making clear their aversion.

HIV-related discrimination has both direct and indirect impacts on engagement in care. Directly, some APHIV shared that they skip doses to hide their status or avoid insults. Indirectly, this type of discrimination can negatively impact APHIV's mental health, such as depression or low morale, which can make them less driven to engage in care. Caregivers living with HIV shared their own experiences with discrimination, emphasizing that feeling stigmatized makes it difficult to accept their HIV status, thus leading to lower engagement in care and high viral loads. Some APHIV shared that they began skipping doses around relatives because they discriminated against them when they saw the APHIV taking drugs. Regardless of gender, some APHIV shared that teachers can be verbally abusive in front of the other students. Several male APHIV reported that teachers have been physically abusive to them because of their status. This makes male APHIV less likely to ask for permission to leave class to take drugs or to go to clinic visits in order to avoid a beating.

"She told me mum, the other students are mocking me because I take drugs but for me I don't mind what they are saying since I always keep my drugs in my box. I talked to the nurse about it and she agreed but later on she told me that even the teachers are making fun of her and anytime she is in a mistake she is always mocked with her drugs." -Female caregiver, CRC, FGD

Experiences with stigma can additionally impact how and when caregivers disclose to APHIV. Many providers expressed sympathy to parents living with HIV, knowing that the public misconception that PLHIV are promiscuous causes some parents not to disclose to their child out of guilt and fear of being blamed. One suggestion from a provider to alleviate this concern while ensuring that APHIV are disclosed to is for caregivers to lie to APHIV about how they contracted HIV, such as saying it was through a blood transfusion, so as to avoid blame that can potentially impact APHIV's adherence. Other providers suggested assisted clinic-based disclosure to aid parents by helping explain the chain of HIV acquisition.

Support groups play an important role in overcoming stigma and consequently helping APHIV manage their health. Some APHIV shared that they only ever saw or heard of PLHIV who were in sick beds or had died, which confirmed the cultural stigma that they were as good as dead. Seeing healthy, asymptomatic ALHIV in support groups helped dismiss this stigma, improve their morale, and exemplify how to lead healthy lives. Support groups also provide APHIV the opportunity to learn strategies others have used to mitigate stigma-related challenges, particularly in boarding schools. Many APHIV in boarding schools shared that support groups helped teach them ways to navigate the minimal privacy they experience. Providers and APHIV both expressed that support groups and caregivers are both important in counteracting misinformation they may hear in school or the community. Many caregivers similarly expressed their part in sheltering APHIV from stigma in the community, such as transporting APHIV to the clinic to avoid drivers noticing that the APHIV is regularly needing rides and then spreading their status through the village.

Environment

One of the biggest challenges named by providers was that many APHIV are orphaned at an early age, and/or switch between multiple caregivers over their life course, with some not even having a primary caregiver. This makes it difficult to coordinate treatment and ensure consistent adherence, not to mention access to basic needs. Changes in primary caregivers often coincides with other environmental changes, such as different schools if the adolescent and/or their caregivers relocate.

The socioeconomic status (SES) of caregivers influences how they are able to support APHIV. Some caregivers noted that they sometimes skipped giving APHIV drugs on days when they could not afford enough food to give the APHIV with their dose. Participants all expressed the difficulty for APHIV to take drugs on an empty stomach and the need to have a proper diet for adherence. Caregivers who are raising partial orphans are more likely to be busy at work during the day without someone else to care for the APHIV at home. Others must travel for work and are away from home often. This results in limited involvement of caregivers to ensure that APHIV are adhering to drugs, and in many cases the adolescent will throw the drugs away, resulting in high viral loads. Having multiple relatives invested in the treatment of the APHIV mitigates this challenge, so that caregivers can go make money to afford food while other relatives are able to ensure adherence at home. Providers noted that, while low SES hinders caregivers' ability to support APHIV, this was not the sole determinant of poor adherence.

"In these sessions, we've seen children who are failing on treatment and they come from wealthy families copy from children who come from very poor families and are doing very well on treatment. And we have seen children who are coming from poor families learn to do well on treatment because they have come to realize that it is not about wealth, even the wealthy ones sometimes fail" - Peer Educator, Homabay

Across participants, stories and beliefs showcased the diversity of experiences. The strategies used to engage APHIV in care were equally diverse, as were the ways that certain relationships influenced APHIV engagement in care. It was often the case that a method that supported engagement for one APHIV had the opposite effect in another. Many participants expressed that the level of support needed by APHIV varied by each unique case.

3.5 Discussion.

The purpose of this study was to examine how social relationships influence engagement in and disengagement from care for APHIV. Findings support existing literature on the importance of individual-level factors as well as the pervasiveness of stigma (Williams et al., 2017). However, in the present data, microsystems played a substantial – and previously undocumented - role in engagement in care.

Among participants in this study, social relationships were found to provide essential supports for adherence and clinic attendance, including hope, courage, patience, and love, as well as logistical support such as reminders and transportation, leading to reduced viral loads and healthier APHIV. While this support can be direct, it is also often performed through the intermediary of mental health. APHIV with improved mental health – who feel loved, wanted, and comfortable – are more willing and motivated to engage in care and desire to achieve and maintain viral load suppression. The connection between engagement in care and mental health was often implicit rather than explicitly stated, but through the larger mosaic of the shared experiences painted by participants, the relationship became clear. It proved critical that APHIV are not simply encouraged to adhere, but to desire to live.

A common theme in the data is that children living with perinatally acquired HIV require additional, or at least continued, support once they reach adolescence, even though many caregivers perceived them to require less support. Many APHIV cited increased negative peer pressure, spending more time outside the house and subsequently being exposed to stigma and misinformation, and having more demanding school schedules, all of which pose new barriers to engagement in care that they did not experience as younger children. Ironically, adolescence also comes with an increased desire for autonomy and a tendency towards rebellion against caregivers, suggestive of the delicate balance between freedom and guidance required during adolescence. These findings back existing literature about how autonomy is complicated for APHIV, who typically rely on caregivers, and that caregivers' conflicting perspectives about how responsible APHIV should be for their care can often result in insufficient or overbearing guidance (Kang et al., 2008).

Our findings align with previous studies suggesting the importance of providers and family in social support (Abramowitz et al., 2009; Kennedy et al., 2004; Vreeman et al., 2010), but add to existing literature by exploring the prominence of peers, friends, other ALHIV, and partners in autonomy support. Existing literature supports the function of these relationships as emotional supports, but the provision of logistical support from the same sources, operationalized as guidance or feedback, has previously been unsubstantiated (Abramowitz et al., 2009). Our findings suggest that friends can provide invaluable logistical support, such as guidance, time reminders, and hiding ART to maintain privacy, particularly for APHIV at boarding school or on school outings, when family are not present. Having numerous forms of support from multiple relationships helps galvanize APHIV by mitigating detrimental effects of unsupportive relationships and environments as well as ensuring engagement across a range of different social contexts (e.g., school, clinic, rural homes, etc.). This finding complements existing literature on the importance of social support for ALHIV (Abramowitz et al., 2009; Casale et al., 2019) by emphasizing the importance of diverse relationships. We also found this to be important for mitigating some of the known negative impacts of socioeconomic status on APHIV (Kang et al., 2008), such that siblings, friends, or relatives are able to provide emotional support in the absence of caregivers who are busy working to provide for their family.

Loving and encouraging relationships, whether from friends, partners, relatives, or caregivers, or support groups, buffered the effects of stigma, discrimination, and harmful misinformation. This finding strengthens the application of existing studies on APHIV in other contexts to those in Western Kenya (Casale et al., 2019; Kaunda-Khangamwa et al., 2020; Williams et al., 2017). Previously undocumented, our findings also suggest the critical nature of mesosystem interactions, particularly those between caregivers and other relationships in APHIV's lives, such as how caregivers were able to improve clinic attendance by talking to teachers and to mitigate peer pressure by monitoring friendships, or how having friends in school helps support APHIV when harmful content about HIV is taught in class.

This study fills an important knowledge gap on how social relationships influence the engagement in care for adolescents with perinatally acquired HIV, reinforcing many existing quantitative analyses suggesting the importance of social supports on APHIV mental health (Abramowitz et al., 2009; Casale et al., 2019; Lee et al., 2015). Findings suggest that numerous interventions could help improve engagement in care, some of which are already implemented sporadically in certain communities in Western Kenya, such as trainings for teachers, counselling for caregivers, WhatsApp groups for ALHIV, and community- and school-based support groups. Improving access to support groups in communities and schools would help foster relationships between APHIV outside of the clinic. While school and community support groups may pose confidentiality challenges, the use of non-clinic based support groups is backed by existing literature indicating that, while support groups are ubiquitously helpful for ALHIV, life outside of the groups is challenging (Mavhu et al., 2013). Utilization of support groups in more contexts can mitigate these challenges.

A few caregivers discussed how counselling and/or caregiver support groups were useful in helping them care for APHIV, which suggests that establishing more structured counseling and support groups for caregivers that educate them on strategies to ensure adherence, clinic attendance, and general management of APHIV health can help them better support engagement. This proposal is supported by an existing study in Western Kenya showing the potential effectiveness of disclosure counselling for caregivers of APHIV (McHenry et al., 2018). Providers should target counseling towards caregivers of younger children with HIV, as well as new caregivers of APHIV, such as when APHIV are orphaned or adopted by new guardians, since our findings indicated that guardians of APHIV often feel less equipped to disclose and care for APHIV. This is an important yet conflicting addition to the literature. Existing literature indicates no difference in morbidity of APHIV based on parental status, and there is limited exploration of the differences in support offered by guardians versus parents in SSA (Groves et al., 2018); Kamau et al., 2012). Further studies are needed to reach consensus. Increased availability of caregiver support groups will also allow caregivers who, regardless of parental status, feel less competent in supporting APHIV to learn from caregivers with more experience, particularly those who have HIV themselves. Initiatives such as the Families Matter! Program (FMP) provide a similar function of helping caregivers and communities develop skills to guide and support ALHIV, which has been successfully adapted in Kenya, and could potentially be adapted for APHIV specifically (Winskell et al., 2016).

It is also advisable for clinics to host more trips for APHIV over school holidays to both improve their sense of togetherness as well as ensure and support adherence over holidays, as a substitute for school trips or traveling to their rural home, when many APHIV struggle with maintaining adherence with the changes in their schedules. This will also help APHIV experience the motivation and hope that trips provide without forcing them to choose between friends or adherence. Existing literature on the impact on viral load suppression of having dedicated spaces for ALHIV supports the promotion of more of these outings (Njuguna et al., 2020).

There are some instances where widespread policy changes may also be influential. Many APHIV indicated that the way they were taught about HIV in the classroom negatively impacted their personal mental health as well as the understanding of their peers, which then indirectly increased the likelihood that these APHIV would skip doses or clinic visits. Having a revised school curriculum to teach all students accurate information about HIV as well as advise them on how to support APHIV would help improve the support APHIV receive from their peers as well as reduce cultural stigma and discrimination throughout the life course. Future studies are needed on the impact of school HIV curricula on HIV-related stigma, as there is a dearth of existing literature (Martin et al., 2022). Improved uniformity of school policy in Kenya would also improve how school staff are able to manage APHIV medication and clinic attendance as well as mitigate the barrier of moving to new schools as a challenge for adherence. Similarly, increased availability of trainings for teachers on how to manage support for APHIV would help improve the support that APHIV experience at school. Chory et al. (Chory et al., 2021) found that teacher training in Western Kenya related to knowledge, attitudes, and beliefs about PLHIV can reduce stigma and reduce gaps in understanding about ALHIV.

Limitations. The data presented a few analytical challenges. APHIV and caregivers tended to use secondhand or hypothetical stories, particularly when answering sensitive questions. While this provided a rich and diverse dataset, it made it challenging to attribute statements to demographic variables. Demographic data was not collected from FGD participants, making it similarly difficult to analyze based on these characteristics. Additionally, providers often spoke in broad terms, where it was unclear whether they were discussing adolescents with perinatally or behaviorally acquired HIV. Because of this, it was difficult to draw comparisons between demographic characteristics, such as mode of acquisition, age, rurality, age of disclosure, and parental status. Where possible, demographic differences are described.

Potential limitations of the study include the absence of those caregivers who were less involved or not at all involved in the care of APHIV. This was mitigated by the inclusion of providers who have experience with a wider array of caregiving styles. Additionally, the study sites were chosen for their large ALHIV populations. This may leave out the perspective and experiences of APHIV in areas with fewer HIV-positive peers and less available youth-centered services. The purposive sampling of APHIV for the qualitative sample by peer counselors and nurses at the health care facilities introduced selection bias, as many participants were older and better able to express themselves.

Conclusions. The findings of this study have significant implications for improving the health and wellbeing of ALHIV in Western Kenya, and potentially in other parts of SSA. Data is consistent with existing studies (Sherr et al., 2018) indicating that APHIV have unique challenges to engagement in care, including parental blame and having to adhere before knowing why. When studies conflate the two, it limits the ability of researchers and clinicians to tailor interventions depending on the mode of HIV acquisition, if needed.

Future studies should examine the relationship between mental health and care experiences among APHIV to garner clarity about how to adapt health and social services to optimize their health outcomes. Triangulating quantitative analysis of viral loads and ages of disclosure along with analysis of social relationships would further support the development of a clearer understanding of how social relationships impact not only engagement in care but care outcomes. Directions for future studies would be to further explore interventions that maximize social support for APHIV, especially ones in which ALHIV with both modes of acquisition co-exist, such as schools and support groups.

Chapter 4: Conclusion & Recommendations

The findings of this study have significant implications for improving the health and wellbeing of ALHIV in Western Kenya, and potentially in other parts of SSA. Findings suggest that numerous interventions could help improve engagement in care, some of which are already implemented sporadically in certain communities in Western Kenya, such as trainings for teachers, counselling for caregivers, WhatsApp groups for ALHIV, and community- and school-based support groups. The following are recommendations based on our findings:

1. Improve availability of community- and school-based support groups to help foster relationships between APHIV outside of the clinic.
2. Establish structured counseling for caregivers to teach strategies to ensure adherence, clinic attendance, and general management of APHIV health. Counselling should target caregivers of younger children with HIV to help prepare them for adolescence and new caregivers of APHIV, such as when APHIV are orphaned or adopted by new guardians, since our findings indicated that guardians of APHIV often feel less equipped to disclose and care for APHIV.
3. Increase availability of caregiver support groups to help caregivers learn from the strategies used by other caregivers, especially those with HIV, and help caregivers feel less competent in supporting APHIV's engagement in care regardless of parental status.
4. Adapt the Families Matter! Program to the experiences and needs of APHIV specifically to help caregivers and communities develop skills to guide and support APHIV.

5. Host more clinic-organized trips for APHIV to attend over school holidays as a way to improve their sense of togetherness, provide motivation, and support adherence.
6. Revise Kenya's secondary school curriculum to teach all students accurate information about HIV as well as advise students on how to support APHIV. This would help improve the support APHIV receive from their peers as well as reduce the cultural stigma and discrimination throughout the life course.
7. Update school policies across Kenyan secondary schools to include appropriate and standardized protocols for how school staff manage APHIV medication and clinic attendance. This will reduce school-based barriers faced by APHIV and mitigate the challenges associated with moving and adjusting to new schools.
8. Develop structured trainings for teachers at secondary schools in Kenya to teach them how to manage APHIV medication and clinic attendance, as well as sensitivity training to help them teach HIV more sensitively in class and respect APHIV's privacy at school.

Improving support for APHIV's engagement in care is ultimately a life and death issue, particularly as APHIV transition through adolescence and into adulthood, when the ability to self-manage their care becomes increasingly essential for achieving and maintaining viral load suppression. We hope that our findings can be used to improve the level of support experienced by APHIV as they navigate their engagement with care.

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