“Your status cannot hinder you”: The importance of resilience among adolescents living with HIV in Kenya

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Abstract

"Your status cannot hinder you": The importance of resilience among adolescents living with HIV in Kenya

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Background: There are approximately 110,000 adolescents living with HIV (ALHIV) in Kenya, of whom 40% have not achieved viral suppression. Despite the increasing availability of adolescent-friendly services, adolescents face barriers, such as widespread stigma, that impact adherence to ART. This study aimed to identify key stigma-related barriers to ART adherence and strategies used by adolescents in overcoming these barriers.

Methods: Data were collected from the Adolescents Living with HIV Research Project conducted by LVCT Health, a Kenyan organization with a programmatic focus on HIV testing, prevention, and care, and gender-based violence. A total of 122 participants were recruited from 3 clinical sites affiliated with LVCT Health in Nairobi, Kisumu, and Mombasa. In-depth interviews (IDIs) were conducted with ALHIV (n = 12). Focus group discussions (FGDs) were conducted with ALHIV (n = 5), peer leaders (n = 3), and adolescents in the community (AIC) irrespective of HIV status (n = 3). IDIs and FGDs were audio recorded, translated, and transcribed. Data were analyzed thematically, with a focus on stigma and resilience.

Results: While AIC and peer leaders focused heavily on adherence barriers and stigma, ALHIV moved beyond stigma to identify resilience factors that enabled them to overcome stigma. Four major themes emerged: 1) knowledge and future-oriented goals can drive motivation for ALHIV to remain healthy; 2) disclosure to others strengthens support systems for ALHIV; 3) medication-taking strategies and strategic disclosure can overcome adherence challenges in school; and 4) a supportive clinic environment promotes continuous adolescent engagement in HIV care. These concepts were used to develop a conceptual stigma/resilience model depicting how resilience moderates the negative effects of stigma among ALHIV.
Conclusions: This study demonstrates the positive effects of ALHIV resilience on ART adherence and illuminates how stigma impacts ALHIV differently depending on their level of resilience. Strengths-based interventions, focused on increasing resilience among ALHIV in Kenya, as well as more formal involvement of adolescent peers to bolster adolescent support, have the potential to improve ART adherence among ALHIV.

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I. Background and Significance

Adolescents represent a highly vulnerable age group in the context of HIV/AIDS, and constitute a growing proportion of people living with HIV globally [1]. Almost 90 percent (approximately 1.5 million) of all adolescents living with HIV (ALHIV, 10-19 years of age) reside in sub-Saharan Africa, the region with the highest burden of HIV globally [2]. In Kenya, which has the joint third largest HIV epidemic both in sub-Saharan Africa and globally [3], HIV prevalence among adolescents is 0.9% (95% CI: 0.6%-1.3%) [4] with 110,000 [88,000 - 140,000] ALHIV [3].

Adolescence is a time of physical growth and sexual maturation, when individuals struggle in navigating relationships and making personal decisions [5,6]. ALHIV face challenges due to living with a chronic disease while transitioning from childhood to adulthood, and often experience high levels of stigmatization, which can impact mental health, disclosure of HIV status, and access to social support systems, and often exacerbates challenges with antiretroviral treatment (ART) adherence and engagement in health services [7]. In Kenya, adolescents and young adults (AYA) are the age group at highest risk for dropping out of HIV treatment, which puts them at higher risk for adverse health consequences including virologic failure and death [8]. Among ALHIV, 39.6% (95% CI: 20.9% - 56.2%) have not achieved viral load suppression [4]. Due to the unique challenges faced by adolescents, it has been recommended that adolescents are provided "adolescent-friendly services" that are separate from those provided for adults living with HIV [5].

The desire to address disparities in ALHIV outcomes and provide adolescent-friendly services has driven development of strategies aimed to improve health outcomes among ALHIV. A random sample of 102 HIV clinics in Kenya examined current strategies used by clinics to improve ALHIV adherence and retention [9], and found that common strategies included offering adolescent support groups (97%), dedicating specific clinic days to adolescents (91%), and offering clinic days on weekends (57%). While many clinics offer adolescent-friendly services, few studies have evaluated the impact of these services on ALHIV outcomes. A recent systematic review examining interventions to meet the needs of ALHIV in low and middle income countries (LMICs) (most in sub-Saharan Africa) found there to be a large gap in

evidence supporting interventions that improve outcomes along the ALHIV care continuum [10]. In order to address this gap, it is important to consider the perspectives of adolescents themselves.

LVCT Health, a non-governmental organization in Kenya providing HIV treatment and prevention services for adolescents, aims to provide patient-centered care by considering adolescent clients' perspectives and using this information to inform operational changes. Identifying key barriers to ART adherence experienced by adolescents accessing services through LVCT Health, and strategies used to overcome these barriers, can inform development of interventions that are directly responsive to patient needs and harness identified resilience strategies. Therefore, the goal of this project was to use qualitative methods to better understand how stigma moderated adolescents' ART experiences from the perspective of ALHIV, adolescents from the community, and peer leaders. Taking into account adolescent perceptions of facilitators and barriers to ART adherence and care engagement will be vital to further improve programming and services and ensure better health outcomes among ALHIV.

II. Specific Aims

The overall goal of this thesis was to identify potential avenues to improve ART adherence and care engagement among ALHIV in Kenya, focusing on how HIV-related stigma is moderated by adolescent resilience. We conducted a qualitative analysis of in-depth interviews (IDI) and focus group discussions (FGD) with AYA participants recruited from three stakeholder groups: ALHIV, adolescents from the community, and peer leaders. The specific aims were:

- Identify barriers and facilitators to ART adherence and care engagement at each level of the socioecological model.
- Compare and contrast how the three participant groups conceptualize barriers and facilitators to ART adherence and care engagement among ALHIV.
- Identify strategies and recommendations to optimize HIV care and treatment among ALHIV in Kenya.

III. Methods

Study design and population

We conducted a qualitative analysis of data collected by the Adolescents Living with HIV Research Project, conducted by LVCT Health in 2018. LVCT Health provides programming focused on HIV testing, prevention, and care and sexual and gender based violence. Their work is embedded within a research policy-practice framework, and has provided technical input in the development of health policies including notably the National Fast-Track Plan to End HIV and AIDS Among Adolescents and Young People [11].

Participants were recruited from clinical sites in three high burden HIV counties in Kenya: Kisumu, Nairobi, and Mombasa [12]. In each county, participants were recruited from one identified health facility which LVCT Health either ran (Nairobi and Kisumu) or worked closely with (Mombasa). The Nairobi and Kisumu clinics are private and provide HIV services to all age groups. The Mombasa clinic is government-owned and specializes in services tailored to AYA. All three HIV clinics have peer leader programs to support ALHIV with ART adherence and retention in care.

Researcher positionality

Two researchers (Millicent Kiruki and Casey Adams) were involved in data analysis and presentation of results. Millicent (MK) is a researcher affiliated with LVCT Health and is based in Kenya. MK has been involved in this research project from project design. MK is well versed on the study context and the culture in each of the study sites. MK is skilled in inquiring about sensitive topics while respecting cultural differences. Casey (CA) is an MPH (Master of Public Health) student at the University of Washington and is based in Seattle, Washington. As a white woman from the United States, CA holds different racial and cultural identities than the research participants. Furthermore, CA entered the project post-data collection and was unable to travel to Kenya due to COVID-19 restrictions. However, CA and MK worked closely together (remotely) for the duration of this project in order to foster collaboration and understanding throughout the research.

Study population

LVCT Health researchers conducted IDIs and/or FGDs with three stakeholder groups: 1) ALHIV ages 10-19 receiving clinical care from LVCT-supported sites, 2) adolescents in the community (AIC) ages 10-19

who worked with LVCT Health programs, irrespective of HIV status, and 3) AYA peer leaders ages 20-24 who were involved in ALHIV services, irrespective of HIV status. Adolescent populations were purposively selected to provide holistic understanding of the facilitators and barriers to HIV services among ALHIV. ALHIV were eligible only if they had been on ART >6 months. Peer leaders in Kisumu and Mombasa were recruited through study clinics, while peer leaders in Nairobi were recruited from other clinics due to low numbers of peer leaders attached to the study site. All participants provided informed consent (if 18 years or older) or assent (for those below 18 years). Parental consent was obtained for those below 18 years.

Data collection

IDIs and FGDs were conducted using semi-structured interview guides, developed by two LVCT Health researchers (MK and MM) with knowledge of the subpopulations. Interview guides focused on eliciting adolescents' views and knowledge on four main topic areas, including 1) ART experiences, 2) barriers to clinic attendance and ART adherence, 3) disclosure of HIV status, and 4) recommendations for how to improve ALHIV adherence and care engagement. Questions were also individualized for each subpopulation to optimize relevance. Peer leader FGDs focused on their role in supporting ALHIV and AIC FGDs included questions to assess perceptions of how ALHIV are viewed and treated in specific contexts, including school, home, and society.

ALHIV participated in both IDIs and FGDs, in order to capture both depth of experiences and group perspectives on key barriers and facilitators of ART adherence. ALHIV who participated in FGDs were members of the same support groups to avoid unintended disclosure. Peer leaders and AIC participated in FGDs designed to generate dynamic discussion about participants' perceptions of ALHIV experiences. Where possible, ALHIV and AIC FGDs were composed of all males or females, because themes related to sexual and reproductive health (SRH) necessitated gender-specific discussion. One FGD in Mombasa was gender-mixed. FGDs and IDIs were conducted in English, Luo, or Swahili, depending on participant preferences. All discussions were audio-recorded, and then transcribed verbatim in the interview language

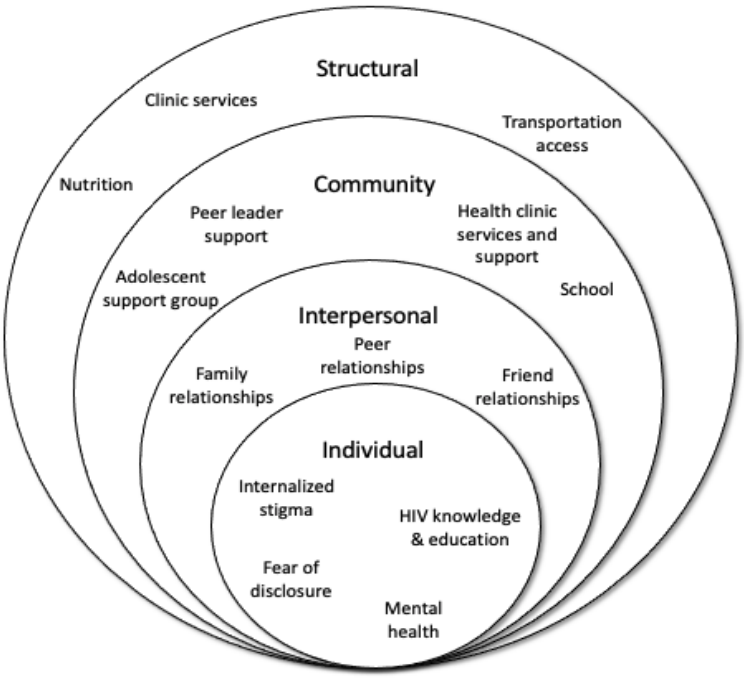
and translated into English when necessary. IDIs lasted an average of 40 minutes, while FGDs lasted an average of 91 minutes.

Data analysis

Data was analyzed using thematic analysis, with the goal of identifying key influences related to stigma and resilience on ART adherence and care engagement among ALHIV. Data analysis was informed by a combination of three existing theoretical models: the social-ecological model (SEM), the HIV stigma framework, and resilience theory. The SEM and HIV stigma framework have been used extensively in prior research focusing on challenges faced by people living with HIV in LMICs [13,14].

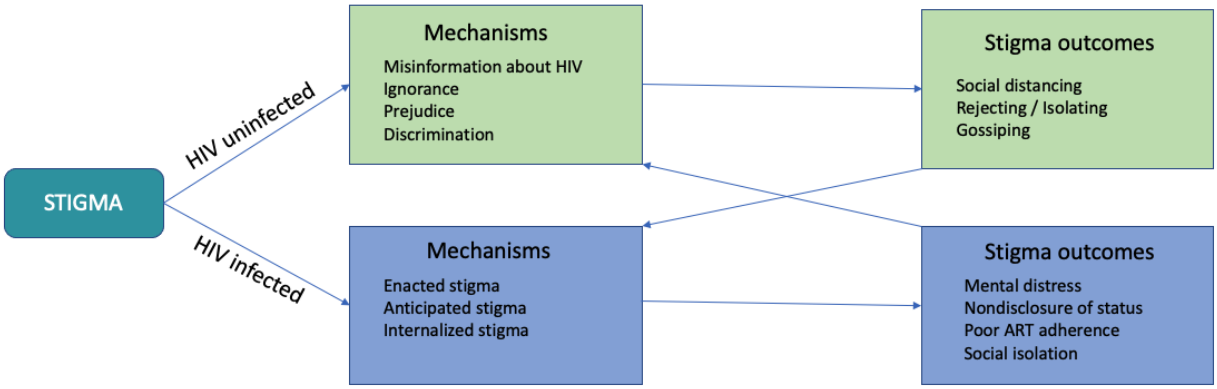
The socioecological model (SEM) has been adapted by many researchers focusing on people living with HIV to illustrate the varied social influences that impact their health behaviors and access to and use of health services [15]. This model conceives of the ecological environment as a nested arrangement of systems [16], with four levels of influence: 1) structural factors, such as policy, laws, and infrastructure; 2) community factors, such as school settings and clinic services; 3) interpersonal factors, such as relationships with family and friends; and 4) individual factors, such as adolescents' HIV-related knowledge, mental health, and internalized stigma (Figure 1). The codebook used for analysis included each level of influence, to examine how the SEM plays out in participants' lived experiences.

Figure 1: Socioecological model depicting factors affecting ART adherence in this study. Adapted from van der Straten et al. [47].



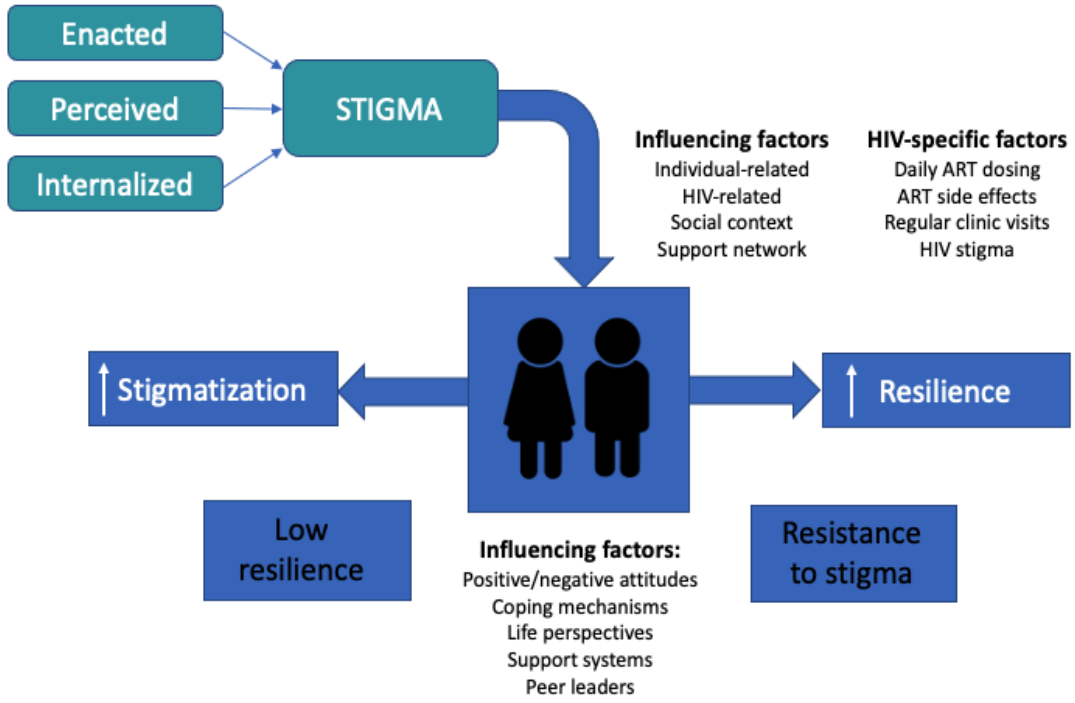
The HIV stigma framework [17] characterizes how HIV-related stigma is experienced by ALHIV through its multi-level effects on adolescents' thoughts and feelings, actions and behaviors, and sense of belonging or community. Individuals with positive HIV status experience various types of stigma (enacted, anticipated, and internalized), which may come from different sources (e.g. community members; the individual) but are all rooted in long-term societal stigmatization of HIV [17]. In the context of HIV, stigma keeps those who are uninfected in a relative position of power because they lack the condition [HIV] that is devalued by society. We adapted the HIV stigma framework [17] to the context of this study (Figure 2).

Figure 2: Model of HIV stigma mechanisms, adapted from Earnshaw & Chaudoir [17]



Resilience theory explores the complex interactions between an individual's assets and resources [18], and has been used in research with adolescents to explore how positive influencing factors (also referred to as "promotive factors") operate in the presence of risk. Lenti et al. [19] created a resilience theory that describes key features of stigma and resilience and factors that influence both. Low resilience is associated with stigmatization, while high resilience demonstrates resistance to stigma [19]. We adapted this resilience theory to depict influencing factors for Kenyan ALHIV participants (Figure 3).

Figure 3: Model exploring how stigma and resilience mutually impact each other, adapted from Lenti et al. [19].



Informed by these theoretical models, the analysis team (CA, MK) used a combination of deductive and inductive methods to inform codebook development. Codes were first developed deductively based on domains and constructs within the frameworks. Inductive codes were then developed through open coding. The codebook was continually revised throughout the coding process through regular team

meetings consisting of coding review, and resolution of differences in code application. To ensure consistency and reliability in code application, five transcripts (a representative sample drawing from each subpopulation and interview type) were coded by each member of the analysis team and compared. All transcripts were coded in *Dedoose* (version 4.12, SocioCultural Research Consultants, LLC) by one member of the analysis team, and reviewed by another member of the analysis team. Discrepancies in code application were noted and resolved through group discussion.

Memos were written during the coding process, and were used to group codes into larger categories and identify themes and sub-themes. Queries were generated for each theme, and extracted data was reviewed and used to consolidate, eliminate, and modify themes accordingly. Identified themes were compared analytically between groups, including: 1) within-group accounts (identifying themes for each IDI and FGD), 2) within-subpopulation accounts (identifying themes specific to transcripts of each subpopulation as a separate unit), and 3) across-subpopulation comparisons (identifying themes across the entirety of the data). Themes were grouped by level of the SEM (i.e., individual, interpersonal, community, structural) to gain a macro level understanding of the similarities and differences that arose.

Ethical approval

Ethical approval and oversight of this study was provided by the AMREF Ethics and Scientific Review Committee (protocol number P396/2017). My analysis for this thesis project was deemed exempt by the University of Washington human subjects committee.

IV. Results

A total of 122 participants were recruited from 3 clinical sites affiliated with LVCT Health in Nairobi, Kisumu, and Mombasa. 38% of participants were from Nairobi (n = 46), 37% were from Kisumu (n = 45), and 25% were from Mombasa (n = 31). Participants were aged 15-24, and 57% of participants were female (n = 70). Additional details regarding participant demographics can be found in Table 1.

Adolescents described how multiple stigma-related barriers and resilience-related facilitators, occurring at individual, interpersonal, and community levels, influenced ALHIV adherence to ART (Table 2). While AIC and peer leader participants focused largely on barriers to adherence, ALHIV described adopting a

strengths-based perspective. ALHIV described how they had developed resilience independently and through support systems, as well as how this resilience manifests in better adherence to ART and clinic attendance. Overall, four major themes emerged related to the interplay between stigma and resilience among ALHIV, crossing multiple socio-ecological levels, and highlighting the complexity involved in removing stigma-related barriers to adherence.

Individual Level: Knowledge and future-oriented goals can drive motivation for ALHIV to remain healthy

The majority of ALHIV discussed experiencing some internalized stigma, which among some adolescents negatively impacted mental health and lowered self-esteem. Constant comparisons to healthy peers, especially siblings or friends, led some ALHIV to have difficulty accepting their status. Many adolescents who expressed mental health concerns and feelings of isolation also cited defaulting on medications. Despite internalized stigma, many ALHIV had come to accept their status and normalize their ART routine. ALHIV discussed how accurate knowledge of ART - including how the medication works, potential side effects, and recommended dosing - helped them understand the importance of consistent use. Many ALHIV trusted that they could continue to lead healthy lives with consistent ART adherence. Some ALHIV cited future aspirations, including educational, career, or family goals, as motivators for taking ART.

> *"I just take them [ARVs] very fast, go to sleep and in the morning I wake up with a lot of psyche and when I go back to sleep, I take them again. It is very easy at that point; when you have something that is driving you to live. When you have something that is pulling you towards life, it is easier than when there is not a lot happening; when things are at a standstill."*
>
> -ALHIV in-depth interview participant, Kisumu

Adolescents also recognized that they needed to stay healthy for the benefit of others. This feeling of personal responsibility also motivated adherence.

> *"I think I'll still take my meds because there's still a lot that I need to do; there are still a lot of people that are depending on me and there are still a lot of people that I need to show that life*

can go on after this."

-ALHIV in-depth interview participant, Kisumu

Generally, a positive outlook among ALHIV and optimism about the future allowed adolescents to overcome internalized stigma and generated an internal motivation to stay healthy that facilitated ART adherence.

Interpersonal Level: Disclosure to others strengthens support systems for ALHIV

A major theme throughout the data was fear of HIV status disclosure. This anticipated stigma made disclosure difficult for many ALHIV, leading some to hide their status from all but their closest family members. AIC and peer leaders particularly expressed that family members and friends would stigmatize ALHIV if their status was disclosed.

ALHIV also described being fearful of disclosure. However, many had positive stories to share from personal experience with disclosure, and the support they received upon opening up to family or friends. ALHIV who had disclosed believed their families were supportive of them and helped them with adherence. For many ALHIV who acquired HIV vertically, their parents or caregivers were aware of their status since babyhood. Support from mothers, and in some cases aunts, was especially important in driving resilience and motivating adolescents to adhere to medication.

"If your parent really cares about you, your status cannot hinder you at all. She will encourage you to finish medicine and you will be okay. She will give you the medicine and give you encouragement, examples, teachings, and education."

-ALHIV focus group participant, Nairobi

For some ALHIV, only their immediate family knew their HIV status. Support from family members was twofold: 1) emotional support including encouraging them and boosting self-esteem, and 2) practical support, such as picking up their medications for them when they couldn't attend clinic and reminding them to take ART on schedule.

"[My mom] is the one who knows when the appointments are; she is the one who tells me when we will come. When I tell her my medicine is about to run out she will tell me to come so that we can make it for the appointment with her because I don't know why I cannot come alone, she is the one who has supported me all the way."

-ALHIV in-depth interview participant, Nairobi

The support that friends provided varied widely among ALHIV, and was based largely on whether adolescents chose to disclose their status. The vast majority of ALHIV recognized the value in disclosing to one or a select few "trustworthy" and "confidential" friends to build a support system. Despite fear of disclosure, ALHIV described overwhelmingly positive responses to disclosing their status to friends. When disclosure did occur, friends helped adolescents adhere to ART by reminding them to take medications, keeping track of appointments, encouraging them, and providing emotional support.

"So if you tell your friend on this particular day she reminds you to go to the clinic. So your friend can set an alarm or she can circle a calendar. So when that day comes, she tells you that you are supposed to go to the clinic, stop what you are doing I'll finish it so you just go."

-ALHIV focus group participant, Kisumu

Some ALHIV had friends who were also HIV positive, which enabled mutual support. One ALHIV described a system she created with her friend in which they used certain code words to remind each other to take ART. This facilitated ART reminders in public without fear of inadvertent disclosure, and it strengthened her relationship with her friend.

When ALHIV disclosed to family and friends, they were able to build personal support systems. Having even one or two individuals to provide emotional support and encouragement and assist with accessing medications when needed proved extremely helpful for adolescents who may otherwise have faced these challenges on their own.

Community Level (School): Medication-taking strategies and strategic disclosure can overcome adherence challenges in school

Adolescents spend much of their time in school, an environment that adolescents described as creating specific challenges for adherence. HIV stigma in school was noted as being extremely high, and had the potential to lead to rejection by peers, gossip, and "special treatment" from teachers that further isolated ALHIV from others.

Most school staff (teachers in particular) were viewed as untrustworthy and unsupportive. Teachers were thought to be uninformed about HIV and to lack understanding of special needs and considerations for students living with HIV. Teachers were viewed as strict and unwavering in their school policies, which oftentimes prohibited students from carrying water or using the bathroom during class. These school policies created barriers to adherence among adolescents whose pill schedule required them to take medication while in school.

Adolescents described overcoming these barriers by employing creative strategies for taking ARVs discreetly to avoid inadvertent status disclosure. For example, some adolescents carried pills in their pockets or socks rather than the noisy pill container, used plastic bags, or wrapped pills individually in paper. Many adolescents found ways to take pills during breaks, at the back of the classroom, or in the bathroom where they wouldn't be seen.

> *"When 2pm reached, I would ask for permission to go to the toilet. And they [teachers] would ask me: 'Why are you carrying your bottle?' And I would say: 'It helps me take my water.' So I would go to the toilet, at the toilet corridor…"*
>
> Interviewer: *"Where would you put them* [the pills]*?"*
>
> *"In some paper, then in my pocket. So I would remove them, wash my hands, take my drugs, then go back to class."*
>
> -ALHIV in-depth interview participant, Mombasa

Strict classroom dismissal policies also created challenges for adolescents who required permission to miss class to attend clinic appointments. Many ALHIV stated that they had been denied being able to leave class and resultantly missed appointments. To overcome school attendance barriers, ALHIV asked their parents to request permission from the school for them to leave or acquired a note from the clinic or

hospital to validate their request. Some ALHIV who feared disclosure to any staff members resolved to miss the entire school day and later explain to teachers that they had been sick.

Some ALHIV were able to build relationships with certain school staff whom they trusted to keep their status hidden and whom they felt could help them navigate adherence in the school setting. These school staff, most frequently school nurses or head teachers (in day schools), or matrons (in boarding schools) were supportive by allowing excused absences, storing medications for adolescents, and reminding them to take ARVs.

> *"There are those in day schools and there is no matron, so you have to tell the principal or the class teachers. So the teacher can remind you when the time comes... or they bring the medication for you."*
>
> -ALHIV focus group participant, Nairobi

ART adherence barriers differed depending on the type of school ALHIV attended: boarding or day school. The majority opinion was that day school improved adherence, as most ALHIV took medication before and after school, avoiding worrying about hiding medications during school. However, some adolescents attending boarding school felt that the routine, especially with consistent meal times, helped them maintain their ART schedule. In addition, those who felt comfortable disclosing their status to their roommates were able to take ART freely in their rooms, which facilitated adherence.

Regardless of the type of school they attended, ALHIV expressed a desire for schools to be more lenient in granting permission for absences. Peer leaders also recognized these barriers, and felt that they could be instrumental in affecting change in school policies that supported adolescents.

Community Level (Clinic): A supportive clinic environment promotes continuous adolescent engagement in HIV care

Most ALHIV felt supported by their health clinics and clinic staff. ALHIV and peer leaders agreed that youth-friendly services were important for engaging adolescents in care and providing a sense of belonging and age-specific support. Various adolescent-friendly services discussed included youth-

specific clinic days, youth friendly clinic staff (including peer support), "youth zones" (youth-specific clinics), adolescent support groups, and treatment buddy systems.

The majority of ALHIV valued youth-specific clinics or clinic days, which created a more comfortable atmosphere for adolescents, and most importantly, provided confidentiality. Youth-specific services also allowed adolescents to meet and socialize with others who shared their status and could relate to their challenges. In particular, adolescent support groups allowed adolescents to share personal experiences and work through problems in a safe space.

> *"We meet different people; we talk together. That bond; I am living with HIV and I find somebody else also, I feel like I'm not the only one that is living with that disease, there are also others. We meet with different people from different places."*
>
> -ALHIV in-depth interview participant, Mombasa

ALHIV had largely positive experiences to share regarding their relationships with clinic healthcare workers (HCW). ALHIV valued clinic staff who were understanding, confidential, non-judgmental, and supportive. They wanted staff who they could "feel free with" to ask questions and share concerns. This type of support helped foster trust between HCW and adolescents, even as many ALHIV were initially wary to open up to HCW.

> *"They* [HCW] *have been encouraging and they have been friendly too...Let's say when you enter there you don't feel like you are in a strange place they have welcomed you and you feel like you are at home."*
>
> -ALHIV in-depth interview participant, Kisumu

Despite the overall positive experiences with HCW described by ALHIV, peer leaders and AIC perceived most HCW to be cold and unsympathetic to ALHIV struggles. Some ALHIV felt that HCW were too strict. Some HCWs were described as scolding adolescents who had missed appointments, causing them embarrassment and impacting their willingness to attend clinic in the future.

An important benefit of youth-specific clinics came from peer leaders, whom ALHIV described as being more relatable and trustworthy than HCW. Peer leader presence created a welcoming atmosphere in the

clinic, where ALHIV were more likely to return, and felt freer in discussing their questions and concerns. Some ALHIV expressed that support from peer leaders encouraged them to take ART consistently, ultimately driving down their viral load.

> *"She [mom] would tell me to take [ARVs] by 8am, but sometimes I would oversleep and miss it. So some of my bottles were full. So our counselor called [peer leader name] encouraged me...told me what it [HIV] is and how to take my drugs, and since then I am fine. My viral load came from 94k to 10k and now it's 150."*
>
> -ALHIV focus group participant, Nairobi

Peer leaders recognized their influence among adolescents and took their responsibility seriously. However, they also discussed a lack of adequate resources and training to effectively do their jobs. They saw greater opportunity for positive intervention given adequate resources and enhanced training. For example, peer leaders requested more complete education regarding ART, including information on side effects, in order to counteract common misinformation among adolescents. In addition, peer leaders suggested that increased home visits would help adolescents struggling with challenges such as denial of their HIV status, fear of disclosure, and/or internalized stigma.

> *"I think door-to-door services can assist because maybe they [HCW] have no way of reaching them [ALHIV]. So when you conduct the door-to-door services, you can find such a person and she [ALHIV] gives you her details and you inform her to meet at such and such a date. She will also make that effort; she can't refuse, she will come."*
>
> -ALHIV focus group participant, Nairobi

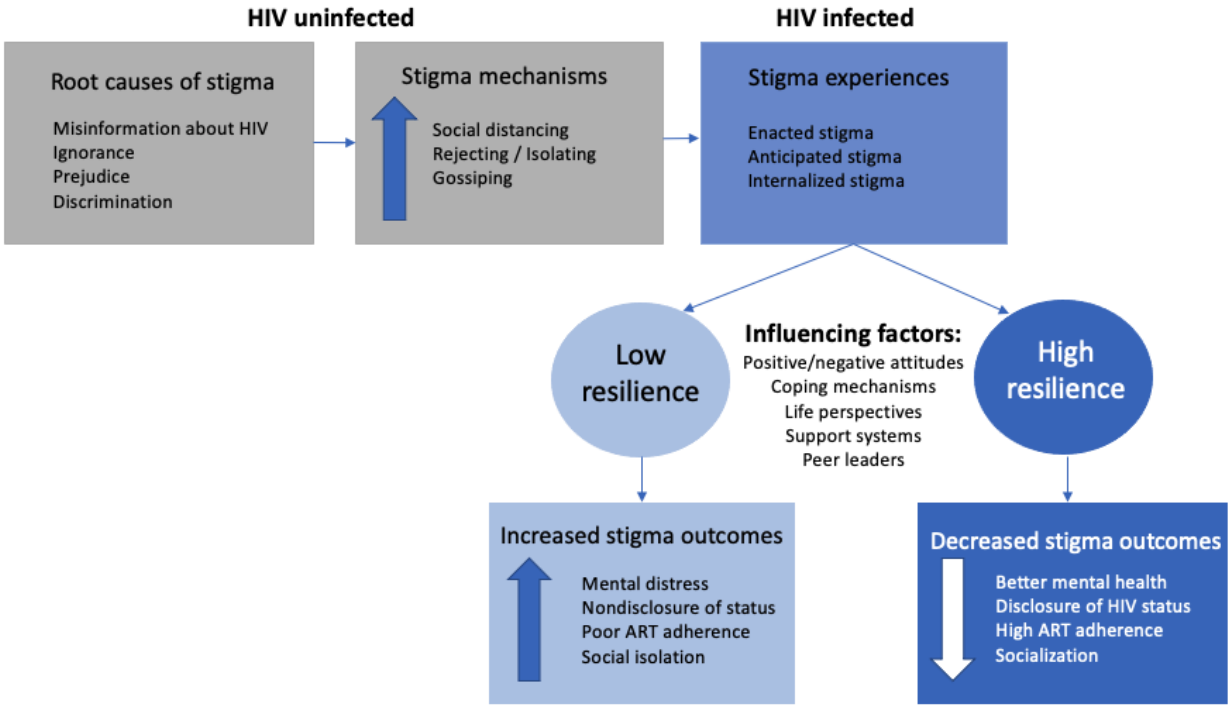
Most peer leaders overlooked adolescents' resilience and strength in overcoming adherence barriers and dealing with adversity. However, peer leaders were passionate about their role in working with ALHIV and expressed a willingness and enthusiasm to learn more and establish deeper relationships with ALHIV.

A conceptual model of promotive factors moderating stigma among ALHIV

Our thematic analysis informed a conceptual model (Figure 4) that describes how stigma and resilience interact among ALHIV accessing LVCT Health services in Kenya. The model explores how, under

certain conditions (e.g. a non-supportive family environment or stigma at school), stigmatization by HIV uninfected individuals may operate to produce adverse outcomes among ALHIV. However, adolescents identified that promotive factors had the ability to moderate the adverse effects of stigmatization. The four themes described above represent influencing factors in different areas of adolescents' lives, in which ALHIV have the potential to overcome stigma and build resilience. However, it is important to note that the presence of negative influencing factors at even one level of the socioecological model (individual, interpersonal, community) may frustrate efforts for ALHIV to achieve healthy adherence outcomes. On the other hand, with more positive influencing factors, ALHIV may exhibit higher levels of resilience and be more successful in staving off stigma outcomes such as poor ART adherence and nondisclosure of HIV status.

Figure 4: Conceptual model exploring the relationship between stigma and resilience in the context of our study population, ALHIV in Kenya



V. Discussion

Findings

This study informed development of a conceptual model (Figure 4) describing how resilience moderates the adverse effects of stigma among ALHIV. Analysis of adolescent experiences allowed better understanding of how adolescents, their support systems, and their communities can support resilience. Our analysis also highlighted how adolescents continue to struggle with ART adherence and care engagement, due to limitations of resilience's moderating effects. Although resilience was a major theme throughout discussions with ALHIV, peer leader and AIC participants were less likely to recognize resilience and its contribution to stigma reduction. Peer leaders and AIC easily identified challenges that ALHIV face, but most did not discuss how ALHIV can be resilient and overcome barriers to achieve ART adherence.

HIV-related stigma has been widely recognized as a barrier to positive health outcomes among ALHIV [7,21,22]. The model derived from our analysis illustrates how HIV-related misinformation, ignorance, prejudice, and discrimination lead to stigma towards ALHIV. That stigma drives social responses such as rejection and isolation of ALHIV, causing stigma to be experienced in different ways, representing enacted, anticipated, and internalized stigma described by Earnshaw & Chaudoir [17]. Unlike the HIV stigma model, resilience theory has been less widely used in the ALHIV literature. However, research has explored how healthy outcomes can occur in the presence of risk factors [25]. Adolescent resilience, or a lack thereof, can make a huge difference in health outcomes. On one hand, ALHIV with positive influencing factors (e.g. a strong support system, healthy coping mechanisms) may have greater resilience, resulting in healthier outcomes (e.g. better mental health, disclosure of HIV status). On the other hand, ALHIV with negative influencing factors (e.g. lack of social support, negative attitude) may lack resilience, contributing to stigma-related outcomes (e.g. poor ART adherence, social isolation).

The SEM has been used frequently to illustrate how social influences impact HIV outcomes, particularly in settings with widespread stigma [13,23,24]. Together, the HIV stigma model and resilience theory coupled with the SEM allowed for a unique, strengths-based approach to inform better understanding of how to harness adolescent strengths at various levels of the SEM to improve ART adherence.

Individual-level facilitators

Few prior studies have examined the relationship between personal resilience attributes such as motivation and optimism in the context of ALHIV. Research among adolescents in the US has shown that a positive outlook may moderate the effectiveness of HIV/STI prevention interventions targeting this age group [26]. In addition, research with Black South African ALHIV found that protective factors at the individual level (e.g. access to information about HIV, self-care) promoted resilience and psychological well-being [27]. Our findings support these studies which highlight the importance of adolescent resilience in the presence of various stressors, including stigma. However, the resilience literature is limited in successful interventions targeting ALHIV; most focus on younger age groups [28,29]. An exception is a study by Dow et al. [29] who conducted an individually randomized group treatment study with HIV-positive Tanzanian youth assessing feasibility of a mental health intervention called *Sauti ya Vijana* (SYV). Results from the study found that SYV promoted resilience by addressing internalized stigma, leading to positive behavior change. This research [29] suggests that similar interventions rooted in individual and group-based sessions may be successful in promoting resilience among ALHIV in Kenya.

Interpersonal-level facilitators

At the interpersonal level, a breadth of research conducted in sub-Saharan Africa shows that disclosure to trusted friends and family members improves outcomes among ALHIV [31–34]. Furthermore, several studies have found that disclosure leading to enhanced social support can bolster individual-level resilience factors, including self-efficacy [32,34]. Qualitative studies with ALHIV in Botswana and Tanzania found that disclosure enabled adolescents to resist HIV stigma and better engage in treatment support, rather than internalizing stigma from peers [32]. A study among ALHIV in Uganda and Kenya found disclosure to be linked to positive individual factors such as self-confidence and personal motivation [34]. Prior research supports that interventions should focus on adolescents' desire for peer acceptance and social connection by teaching ALHIV how best to disclose to trusted friends and family members and navigate social scenarios [6]. Besides adolescent-focused interventions, interventions should engage adolescents along with their support systems to address misinformation and stigma and

enhance psychosocial support to improve adolescent adherence [35]. LVCT Health has engaged both HIV-positive and HIV-negative individuals in programming, but a larger effort is needed to include a wider population of caregivers, peers, and school staff to reduce community stigma.

Facilitators in the school environment

Although many studies have focused on schools as potential intervention sites for HIV prevention, testing, and education [36–38], few studies have focused on how ALHIV can build resilience in school settings. Several PhotoVoice studies conducted with ALHIV in schools support our findings that ALHIV can develop coping strategies in school settings [39,40], highlighting the important role of friends as resources to help them cope with adversity in school [40]. Similar to adolescents in our study, adolescents in other studies have perceived teachers as insensitive, strict, and unsupportive. Training school staff, and relaxing attendance policies, may enhance understanding of the special considerations and needs of students living with HIV, and improve inclusivity of ALHIV in classrooms. The Red Carpet program, a school-based intervention in Kenya aimed at building the capacity of adolescent health advocates (i.e. school staff) through peer-led trainings [41], demonstrates that interventions focused on policy changes may improve understanding among school staff and drive internal policy changes that improve HIV outcomes among school-going ALHIV.

Facilitators in the clinic environment

Our findings showed that health clinics had the potential to build resilience among ALHIV, in line with research demonstrating the positive impacts of adolescent-specific services on health outcomes [42,43]. Health clinics can support ALHIV in a variety of ways, by helping them gain knowledge of SRH resources [44] and teach strategies for disclosure and interpersonal skill-building [45]. Our findings suggest that adolescents feel more comfortable with HCW who are warm, non-judgemental, provide comprehensive information, and build trust with patients. This suggests that HCW should focus on building positive relationships that foster resilience and promote continued adherence. One study conducted with a small sample of HIV-positive adolescents and adults in the US demonstrated that

providers who believed in the inherent strength of their patients were better able to foster resilience among patients [46].

In clinic settings, various forms of peer support programs have been shown to be effective in improving health outcomes of ALHIV by improving ART adherence [47]. One systematic review of ALHIV interventions [48] found that several studies that involved peer-delivered mental health interventions resulted in increased ART adherence in intervention compared with control groups [29,49,50]. This suggests that peer leaders can drive successful interventions focused on improving ALHIV ART adherence. LVCT Health already utilizes peer leader programming. However, our research highlights the need for increased peer leader education, resources, and compensation. Better support for peer leader programs would allow peer leaders to gain a more holistic view of adolescent experiences, and allow them to recognize their role in supporting ALHIV in building resilience internally and through support systems. In addition, peer leaders who are HIV-positive can be encouraged to disclose their status to adolescent patients to serve as role models and provide examples of how they overcame stigma and other challenges themselves.

Limitations

The majority of adolescents sampled were vertically infected, and perspectives of ALHIV infected through horizontal transmission may not be as well captured. Furthermore, FGDs conducted among AIC and peer leaders included adolescents regardless of HIV status, which may have limited contributions of certain participants (especially HIV-positive individuals). Our analysis was focused on the experiences of adolescents and young adults. Analysis of parent/caregiver or HCW perspectives could have added additional insight into stigma and resilience experiences, and should be considered in the future. Finally, these results may not be generalizable to other populations or settings in Kenya not affiliated with LVCT Health or with less access to tailored services. However, major strengths of this study include its qualitative methodology that centered the perspectives of three AYA participant groups through both FGDs and IDIs.

Dissemination of Findings

The researchers will present results during a dissemination meeting with LVCT Health staff and provide with them the written results. With better understanding of adolescent patients, LVCT Health will be able to improve existing programs to better fit the needs of ALHIV and consider different approaches to build resilience. They will also be able to better design future adolescent-targeted programs and forge new community partnerships to enhance support for ALHIV.

VI. Conclusion

This study demonstrates the resilience of ALHIV despite facing challenges that stem from different sources, many of which are rooted in stigma. The researchers' creation and use of a conceptual model sheds light on how societal stigma impacts ALHIV differently depending on their resilience. Our findings suggest that ALHIV can actively cope with challenging social circumstances through their individual resilience, social support of family and friends, and garnering support in school and clinic settings. ALHIV themselves were better able to identify their own resilience as compared to their peers. With better understanding of ALHIV resilience, peers may be able to strengthen adolescents' existing sources of resilience to shape positive adherence outcomes. For example, peer leaders can encourage ALHIV in disclosing their status to trusted family and friends in order to strengthen their support systems, while AIC may become a part of the support systems that allow adolescents to improve adherence. This study highlights the need for strengths-based interventions that take into consideration the individual, home, school, and healthcare contexts, as well as more formal involvement of adolescent peers to bolster adolescent support and enhance HIV adherence.

VIII. References

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Table 1: Participant characteristics

Participant group	Type (n)	Site	Participants (n)	Female n (%)	Age range (years)
ALHIV	FGD (2)	Kisumu	19	11 (58)	15-19
ALHIV	FGD (1)	Mombasa	11	6 (55)	15-19
ALHIV	FGD (2)	Nairobi	19	9 (47)	15-19
Peer leaders	FGD (1)	Kisumu	11	6 (55)	20-24
Peer leaders	FGD (1)	Mombasa	8	4 (50)	20-24
Peer leaders	FGD (1)	Nairobi	12	6 (50)	20-24
AIC	FGD (1)	Kisumu	11	11 (100)	15-19
AIC	FGD (1)	Mombasa	8	0 (0)	15-19
AIC	FGD (1)	Nairobi	11	11 (100)	15-19
ALHIV	IDI (4)	Kisumu	4	2 (50)	16-19
ALHIV	IDI (4)	Mombasa	4	2 (50)	15-19
ALHIV	IDI (4)	Nairobi	4	2 (50)	15-18

Table 2: Perceptions of barriers and facilitators to adolescent ART adherence among participant groups.

SEM level	BARRIER	ALHIV	AIC	Peer leaders	FACILITATOR	ALHIV	AIC	Peer leaders
Individual	ALHIV experience internalized stigma, which manifests in isolation and a lack of sense of belonging	X	X	X	Self-motivation and a positive attitude drive pro-health behaviors	X		
	Internalized stigma leads to low morale, negatively impacting ART use	X	X	X	Presence of future life goals (i.e. career goals, family goals) is a motivator for adherence	X		
	ALHIV constantly compare themselves to peers without HIV, negatively impacting mental health	X			Knowledge is power, and accurate knowledge of ARVs can improve adherence	X		X
Interpersonal	Many parents/families will stigmatize, mistreat, or desert ALHIV when they find out their status		X	X	Family members offer support in the form of encouragement, reminders to take ART, and help picking up medication	X		
	Stigmatization within families often leads to community-wide stigma		X	X	Friends are generally supportive when disclosure occurs; support includes encouragement and reminders to take ART	X		
	ALHIV struggle with disclosing their status due to anticipated stigma	X	X	X	Support of an HIV-positive friend or family member encourages better adherence and improves mental health	X		X
	Lack of disclosure to others can lead to social withdrawal and mental health concerns (i.e. anxiety, depression)	X			Having the support of even one person (family, friend) can motivate ALHIV to engage in pro health behaviors	X		X
	ALHIV default on medication (skipping or delaying ART) due to fear of status disclosure while with friends or family	X	X	X	Disclosure is challenging but the support received as a result is worth it	X		X

	Disclosure to friends causes friends to stigmatize/isolate ALHIV or become overly attentive		X					
Community	School classmates and teachers stigmatize ALHIV and spread gossip	X	X	X	ALHIV who seek support from school staff (head teachers, matrons, nurses) are granted permission to attend clinic appointments	X		
	ART medication packaging is stigmatizing (i.e. seen as a symbol of HIV) and discourages ALHIV from carrying pill bottle at school	X	X	X	In school settings, creative solutions for carrying ART discreetly facilitates adherence (ex: carrying single pills in pocket rather than pill bottle)	X		
	Teachers separate students with HIV from other students, causing social isolation for ALHIV in school	X	X	X	Positive relationships with HCW generate trust and encourage care-seeking among ALHIV	X		
	Distrust of teachers causes challenges asking for permission to attend clinic during school hours; this can lead to missed appointments	X			Peer leader encouragement and support is effective in motivating adherence, especially to attend clinic	X		X
	Fear of disclosure at school makes ART adherence difficult for those whose pill regimens overlap with school hours (especially boarding school students)	X	X	X	Adolescent support groups foster peer connection, support positive mental health, and improve adherence	X		X
	HCW are usually older, judgemental, cold, and unrelatable to ALHIV		X	X				
	HCW scold ALHIV who have missed appointments or have poor adherence, impacting their desire to attend clinic	X		X				