

Exploring the role of social support in viral suppression among adolescents
and young adults living with HIV in Homabay County, Kenya

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Abstract

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Introduction

In 2022, there were 1.3 million new HIV infections reported globally, with 50% of these occurring in sub-Saharan Africa. In Kenya, adolescents and young adults living with HIV (YLH) accounted for 38% of new HIV infections in 2020. Viral suppression among YLH lags other age groups, with 89.2% unsuppressed compared to 94.9% among adults nationally. Social support plays a key role in influencing viral suppression. In this study, we explored how different forms of social support influence viral suppression among YLH with and without viral suppression.

Methods

This was a qualitative study that utilized in-depth interviews and focus group discussions. Purposive sampling was used to recruit 30 YLH for individual interviews, 18 parents/caregivers, and 18 healthcare workers for focus group discussions (FGDs) at three health facilities, in Homabay Kenya. Card sorting activities were employed during interviews and FGDs to identify values and tradeoffs in social support decision-making. Thematic analysis was used to identify patterns of social support impacting viral suppression.

Results

The study revealed that YLH require consistent instrumental, informational, and emotional support to manage their HIV effectively, with significant challenges identified in maintaining treatment adherence due to inconsistent support and stigma, especially in school environments. Inadequate support negatively impacted medication adherence and viral load management, emphasizing the need for continuous caregiver and healthcare provider involvement. Recommendations include providing age-specific counseling by healthcare providers to deliver emotional and informational support tailored to the varying capacities and understanding of younger and older YLH. Integrating HIV care in schools and offering incentives can provide the practical assistance needed to strengthen treatment adherence. Continuous education for caregivers and YLH, along with the establishment of peer support groups, is necessary to reduce community stigma and build stronger social support networks. Comprehensive social support systems are essential to improve health outcomes and ensure effective HIV management for YLH.

Conclusion

Maintaining a robust social support system is essential for YLH, irrespective of their viral suppression status. Interventions among YLH should prioritize comprehensive support strategies, encompassing practical assistance, emotional encouragement, and guidance, to address their needs holistically across all treatment stages.

INTRODUCTION

In 2022, there were 1.3 million new HIV infections reported globally, with 50% of these new infections occurring in sub-Saharan Africa¹. In Kenya, adolescents and young adults living with HIV (YLH) accounted for about 38% of new HIV infections². Homabay County is disproportionately affected by HIV, with HIV prevalence four times higher (18.5%) than the national prevalence². Among people living with HIV (PLH), poor adherence to antiretroviral treatment (ART) results in high viral load, immunosuppression, and opportunistic illnesses, affecting the quality of life and heightening the risk of HIV transmission^{3,4}. Optimizing health outcomes and ending the HIV epidemic will require novel strategies to support PLH to achieve viral suppression. This is especially true for YLH, who experience higher rates of viral non-suppression than adults⁵⁻⁷. Over 95% of adults living with HIV are virally suppressed in Homabay, compared to only 93% of YLH⁸, highlighting the need for additional interventions to support reaching UNAIDS 95-95-95⁹ goals among YLH.

Studies have shown that social support is an essential facilitator of ART adherence and viral suppression for PLH¹⁰⁻¹³. Cohen and Wills developed a model that describes the impact of social support on health outcomes¹⁴. Their Main Effect Model posits that social support can have a direct positive effect on an individual's well-being by providing positive experiences, predictability, stability, and recognition of self-worth, irrespective of the presence of stress. The model also acknowledges that the overall well-being of an individual is further strengthened by having a large and stable social network¹⁴. The Main Effect Model includes four main domains characterizing how an individual receives social support: informational, instrumental, emotional and appraisal support.

Within the YLH movement of “*nothing for us without us*”, it is important to engage youth in understanding how social support can be used as a strategy to improve viral suppression. *Card sorting* is a participatory method that has been used in qualitative research to actively engage participants in the decision-making process and encourages them to articulate the reasoning behind their choices¹⁵⁻²⁰. Card sorting is an invaluable tool for researchers to gain insights into how users perceive and prioritize specific topics

of interest²⁰. This method has been used to understand decision-making rationale in multiple settings related to HIV treatment and prevention. In Lesotho, card sorting was used to understand the opinion of stakeholders on obstacles and effective interventions needed to attain widespread Pre-Exposure Prophylaxis (PrEP) coverage²¹. In Tanzania, it helped to identify the attitudes and preferences that could affect the acceptance of PrEP among adolescents and young women²². Similarly, in Mozambique, it was used to evaluate the challenges and facilitators toward ART adherence and to gain insights into the individuals heavily relied upon by adolescents and young people in various health-related scenarios²³. Despite the perceived benefit of understanding decision-making rationale, studies have yet to explore card sorting approaches to evaluate the impact of social support on viral suppression among YLH.

We conducted a qualitative study using a card sorting approach to assess the direct influence of informational, instrumental, emotional, and appraisal support^{11,15} on YLH viral suppression. Our goal was to understand how participants evaluate and prioritize social support options based on their values and gain valuable insights into how social support models can be better tailored to meet the care needs of YLH.

METHODS

Study design and population

The study was conducted in two health facilities located within fishing communities (Nyandiwa and Suba hospitals), and one health facility from the mainland (Magunga hospital) to ensure a diverse range of experiences. Fishing communities are associated with high HIV prevalence and mobility patterns²⁴ which can significantly impact the accessibility and utilization of social support resources. By including different types of communities commonly found in Western Kenya, our study hoped to capture the full range of factors that influence support networks among YLH in this region.

Data Collection

We used purposive sampling to recruit YLH ages 15-24 for participation in in-depth interviews (IDIs), and parents/caregivers of YLH and healthcare workers (HCWs) for participation in focus group discussions (FGDs). The study team worked with facility-based healthcare workers and community health volunteers to recruit eligible participants. HCWs identified eligible YLH and parents/caregivers and referred them to study staff for consenting and recruitment. HCWs from participating clinics were recruited by the study team. Thirty YLH were recruited to include an equal number of YLH with suppressed (≤ 20 copies/ml) and unsuppressed (> 1000 copies/ml) viral load and of varied ages (15-18, 19-21, 22-24). The study also included 6 parents/caregivers of YLH from each of the three communities and 6 HCWs from each participating facility who had been working in the same facility for at least one year and provided services to YLH.

IDIs and FGDs were conducted between December 2023 and February 2024 using semi-structured discussion guides designed to explore: 1) the impact of social support on HIV care and treatment, HIV disclosure, and viral load suppression, and 2) barriers, facilitators, and strategies for improving social support for YLH across socioecological levels. Conducting both IDIs and FGDs deepened our understanding of the decision-making process among YLH particularly, in relation to the key influences on their social support options as well as the interpersonal and community-level barriers to these influences. The IDIs and FGDs were conducted in Dholuo or English based on participants' preferences, by two trained qualitative researchers. Interviews were audio recorded, transcribed, and back-translated into English as necessary.

All data collection was grounded in the Main Effect Model and focused on the four functions of social support, namely instrumental, informational, emotional, and appraisal support. Based on literature reviews of barriers and facilitators to viral suppression, we adapted a model that defined each core area of support within the context of HIV treatment for YLH (Figure 1). Informational support involves providing advice and information about HIV treatment and care to improve knowledge and understanding, potentially leading to better viral suppression outcomes. Instrumental support includes

tangible assistance such as help with transportation, medication management, and food, which is crucial for YLH. Emotional support involves expressions of empathy, love, trust, and care, which reduce stress and improve mental health, thereby promoting adherence to treatment and retention in care, leading to better viral suppression outcomes. Appraisal support offers feedback and validation to boost self-esteem and promote self-efficacy, helping YLH feel more in control of their health¹⁵. We used this adapted model to guide the development of a card sorting exercise used during IDIs and FGDs.

Card sorting was conducted at the start of each IDI and FGD to identify values and value tradeoffs when making decisions about social support options. The decision-making rationale was then further explored through a discussion of card placement choices. We used a hybrid approach that allowed participants to use predefined cards based on our adapted Main Effect Model, as well as create their own cards to capture factors important in managing YLH health that were not already present (Table 1). Participants sorted cards into four categories: 1) who should provide support, 2) what support should be provided, 3) when is support needed, and 4) how should the support be provided. When sorting cards, participants were asked to rank their placements based on perceived level of importance (most important, somewhat important, not important).

Table 1: Predefined categories of cards

WHO	WHAT	WHEN	HOW
<ul style="list-style-type: none"> •Mother •Father •Sister •Brother •Cousin •Girlfriend •Boyfriend •Wife •Husband •Peer •Health provider •Grandmother •Grandfather •Aunt •Uncle •Teacher 	<ul style="list-style-type: none"> •Informational support •Instrumental support •Emotional support •Appraisal support 	<ul style="list-style-type: none"> •ART treatment initiation •Follow-up ART treatment •During viral load monitoring •During high viral load phase •During viral load suppression phase 	<ul style="list-style-type: none"> •Financial assistance •Transportation assistance •Housing support •Nutritional support •Medication adherence support •HIV treatment information •Education on HIV treatment options •Guidance on disclosure & HIV-related stigma •Information on the latest medical advancements in HIV treatment •Counseling services •Family involvement in treatment and acceptance •Peer support groups •Celebrating milestones

We used a thematic analysis approach²⁵ to identify, analyze, and interpret patterns of meanings from the data. Semi-structured and FGD transcripts were uploaded into Dedoose software for data management and analysis. The codebook was collaboratively developed by a core team of analysts (RA, LO, IM). An initial code list was generated deductively from our adapted Main Effect Model and cards used during the sorting exercise. The codebook was subsequently refined to capture concepts directly emerging from transcripts that were not yet included through a detailed review of transcripts. The preliminary version of the codebook was applied to an initial set of transcripts (n=6) by a two-member team (RA, IM). Codes and their corresponding definitions were refined by discussing the interpretations and coding decisions to effectively reach a consensus on a final version of the codebook. The final version of the codebook was used to independently code all transcripts. After coding, queries were used to abstract supporting information for different elements of social support and compare key influences on social support within and between participant groups. Findings were summarized into larger themes that characterized how social support influences viral suppression.

ETHICAL CONSIDERATIONS

This study was reviewed and approved by the University of Washington Institutional Review Board (STUDY00018432) and the KEMRI - Scientific Ethics Review Unit (KEMRI/SERU/CMR/P00254-08-2023/4855). All participants ≥ 18 years provided written informed consent, participants ages 15–17 years provided written assent and a parent/caregiver provided written parental permission consent.

RESULTS

A total of 30 YLH participated in IDIs and 18 parents/caregivers of YLH and 18 healthcare providers participated in 6 FGDs. YLH were a median of 19 years of age (IQR: 17 - 22), and the majority (60%) were female and single (61%). Most (67%) had attained secondary-level education. Twelve (40%) YLH had high viral load ($> 1000\text{cps/ml}$), while the remainder were virally suppressed. Among parents/caregivers median age was 41 years (IQR: 38 - 54); they included mothers (39%), fathers (33%), spouses (11%) and grandmothers (17%) of YLH. Healthcare workers included facility-in-charges (5%), clinicians (28%), nurses (28%), adherence counselors (17%), and peer educators (22%). Table 2 summarizes additional demographic information.

In the card sorting exercise, both groups identified mothers as the most important support figures, with 40% of YLH and 83% of FGD participants sharing this view, while boyfriends were considered less important, particularly by YLH (47%). Support types such as medication adherence were highly valued, with 16% of YLH and 28% of FGD participants rating it as most important. Instrumental support was also significant, noted by 37% of YLH and 33% of FGD participants. Emotional support was crucial for 33% of YLH. Additionally, 53% of YLH emphasized the importance of support during high viral load periods. While FGD participants unanimously prioritized ART initiation (100%), viral suppression was seen as less critical by 83%. These findings are detailed in Tables 3 and 4.

Characterization of Social Support Structures

All YLH emphasized the importance of receiving three types of social support - instrumental, emotional, and informational - for effectively managing their HIV. YLH identified key elements of instrumental support as including medication adherence reminders, access to nutritious food, financial assistance for transportation costs, and material aid such as clothing. They understood the significance of receiving consistent instrumental support during all phases of HIV treatment, including support from healthcare providers during follow-up visits. This support included educating them, monitoring medication adherence, offering encouragement, and addressing challenges faced at home.

I want support during routine follow-up ART treatment because the health providers are always monitoring my medication adherence and viral load. They are helping me to bring my viral load down. They call me and ask how I am managing my medication back at home and if I am taking the drug as required. They encourage me and ask me about the challenges I am going through at home, and that makes me feel good.

Male, 22yrs, HVL

They recognized the importance of instrumental support for maintaining treatment adherence to prevent complacency and ensure sustained suppression of viral load levels.

It is usually a very hard task to bring a high viral load to a suppressed level. I relaxed after achieving suppression and that is why I feel getting the medication adherence support during the suppression phase will make me not to relax again and give up on my medication in any way.

Male, 17yrs, HVL

YLH with high viral loads (HVL) specifically emphasized the value of receiving additional instrumental support during times when their viral loads were high. This was not recognized as consistently as a specific need among those with currently suppressed viral loads (LDL).

The reason why I picked during the high viral load phase is because I currently have high viral load which means my viruses have increased. So, the health providers have been telling me to come to the clinic every day to take my drugs because missing medication can cause one to have a high viral load. So, for me to maintain a low viral load I should take drugs properly and if I take my drugs properly until the HIV is LDL, I together with my parents, will be happy because taking drugs until one reaches LDL is difficult, it's not an easy thing.

Female, 15yrs, HVL

YLH expressed a desire for informational support to empower them with the knowledge and understanding needed to make informed decisions about their treatment and care. YLH acknowledged the importance of staying informed about the latest medical advancements and treatment options in HIV care.

Somewhat I need access to reliable information about HIV because I need to be kept aware of the improved versions of treatment. Information on the latest medical advancements in HIV is also key since we are young people and must go with the latest trends.

Female, 22yrs, LDL

For emotional support, YLH expressed the desire for family involvement in their treatment, as well as reassurance from attending peer support clubs. Regardless of viral load status, YLH considered mothers, grandmothers, and healthcare providers as primary sources of emotional support, providing emotional encouragement in addition to practical assistance and guidance on how to cope with HIV. They felt support from these individuals fostered deep inter-personal connections and built the foundation for trusted relationships. YLH referenced the receipt of existing support from these individuals as the rationale for desiring ongoing support from these same individuals.

I picked on my mother because she is the one who knows me since childhood and no one knows me better than her. I feel my mother can best help me by reminding

me about my treatment. She also needs to continue with counselling especially when my viral load rises. She needs to be asking me continuously whether I am adhering well so that I achieve viral suppression. She understands me better and I equally trust whatever she tells me”.

Female 19yrs, HVL

Siblings were viewed as important secondary sources of emotional support when primary support individuals were not available.

My sister has been able to listen to how my mother counsels me on certain aspects of HIV treatment and so if my mother is away, she can stand in to encourage me to adhere to my treatment and counsel me when my viral load is high because I worry a lot when it is high and struggle to bring it down.

Male, 15yrs, HVL

YLH did not identify a need for appraisal support. They questioned the value of external appraisals and expressed skepticism about others' motives behind praise, preferring to rely on their internal standards or experiences.

Whether appraised or not, I don't think it can make any difference in my life with HIV. The morale to continue adhering well is there whether I am appraised or not because some people don't mean what they say.

Female 18yrs LDL

I don't need to be appraised to live a healthy life. I think I have gone through a lot in life and in living with HIV, I know what is required of me, so I don't need any appraisal.

Female, 16yrs, LDL

Impact of Inadequate Social Support

YLH described how inadequate social support negatively impacted their medication adherence and viral load status. They described how feelings of isolation, increased stress, and difficulties in adhering to HIV treatment plans could arise in the absence of social support, thereby impacting overall health outcomes and compromising viral suppression efforts. They noted how lack of social support from the time when they were learning about their HIV status through current ART treatment experiences could have a negative impact on viral load. Their lack of access to and use of social support was influenced by several factors including the absence of essential information about managing ART (informational support), limited monitoring support (instrumental support), and stigma and negative educational frameworks (emotional support). The challenges faced in accessing social support that were identified by YLH were also confirmed by caregivers and HCWs.

Participants described how informational and emotional support could sometimes work in tandem to influence YLH outcomes. YLH described how failure to provide accurate information could result in emotional distress, leading to lack of adherence to medication regimens. YLH participants recognized that it was important for parents or caregivers to provide reliable information in a timely and comprehensive manner. By providing access to information, caregivers would support YLH to make informed decisions and give them the opportunity to be collaborators in managing their HIV care. In contrast, lack of timely access to accurate information could create challenges, and create lifelong challenges with trust and negatively influence parental relationships, making it more difficult for YLH to accept and manage their HIV. The experience of first learning about their HIV diagnosis was recognized as a specific time point in HIV care where informational and emotional support were linked together in their influence on HIV outcomes among YLH.

“I was taking drugs all the time... so I became curious and asked “Mum, why am I taking drugs?” She told me, “You have TB”... then after around two months we came to the clinic and after being taught they told us, “Go and ask your parents why you are taking medication”. So I went and asked “Mum, why am I really taking

drugs?” and she was like, “Because you are HIV positive and you have to live with it”... It was very terrifying... I was like “I will take drugs for the rest of my life!” At first when she told me that I was having TB I was like “TB gets cured, I can take drugs even for a year and then it’s cured”. But when she told me that I was HIV positive, it was very painful and stressful. Taking medication became difficult at some point because all the time I was just thinking of how my mother lied to me and how I was going to die”.

Male, 19yrs, LDL

You know there is a certain age that once a child attains, the parent/caregiver should tell them why they are taking those medicines [ARVs]... some parents/caregivers lie to them that they are taking medicines [ARVs] because they have chest problems and as the adolescents grow up, they discover that they are the only ones in the house taking those medicines [ARVs] and yet they have never even experienced any problem with their chest, and that is the way they will stop taking them [ARVs].

Caregiver FGD5, Father

YLH noted that the involvement of caregivers in ensuring medication adherence can significantly impact subsequent health outcomes. They emphasized the critical role of instrumental support, particularly in monitoring medication adherence, for effective management of viral load. Conversely, neglecting adequate monitoring of medication adherence for YLH could lead to negative consequences, including the risk of treatment non-compliance.

After some time, my viral load rose again and the provider invited us again for a counseling session with my aunt. She was warned that if she didn’t monitor my adherence, the health providers would transfer me back to my original health facility. After that, my aunt started monitoring my adherence and indeed the viral load went down as a result of that. Again, she later left me to monitor my adherence claiming that I was now old enough to do that on my own. I entirely depended on

the radio to observe pill time but at times the radio could run out of battery and it could take longer before new batteries were bought...[silence]... and so during this phase, I was really struggling to know the right time to take pills and even my viral load was bad because I couldn't observe my drug schedules.

Female, 15yrs, LDL

There is lack of close monitoring of YLH. Nobody bothers whether they attend clinic and even if they attend clinic nobody bothers to find out if they are taking their medication appropriately. Some of them collect drugs and throw them away in the bush.

Caregiver FGD1, Mother

Participants described situations where instrumental and emotional support were simultaneously lacking, negatively impacting YLH medication adherence and subsequent viral suppression. Specifically, YLH described how school schedules lacked alignment with clinic schedules, making it challenging for them to return to the clinic for medication refills. and leading to prolonged periods of non-adherence. In addition to non-alignment between clinic and school schedules, limited opportunities to access medication discreetly within the school environment created fears of experiencing rejection and stigma from peers and school staff preventing consistent adherence to medication storage. Systemic challenges were highlighted especially in boarding schools, including inadequate support structures, and punitive measures that discourage YLH from managing their health effectively.

I stayed at school for about four months meaning I missed taking pills for about a month. The one month that I stayed in school while sitting exams, I didn't have pills and I couldn't be given permission from the school to go for a refill because it was during the exams and no student was allowed to leave the school during that time. Later when I finished my final exams and got home, I just developed this fear of coming to the hospital and did not show up again for another month. I can say I

did not use drugs for about two months. I know it is not a good thing, and that's why I am doing poorly in my treatment.

Male, 19yrs, HVL

But when they transition to a new environment like boarding school, the Ministry of Education is not so concerned with children who are on HIV care and treatment. They don't have a good structure for finding out if the students admitted have special health needs. So, there is a disconnect and that is why so many of the school-going YLH in boarding schools are facing high viral load issues because they carry drugs to schools, they do their best to go with the drugs and keep them in their suitcases. However, the time given for YLH to stay in the dormitories is very limited for YLH to take drugs appropriately and there is a lot of stigma in boarding schools. Students are not allowed around the dormitory, when one is seen around the dormitory, it is punishment. No one bothers to hear these students. Even if somebody is bothering to hear them, the environment is not good. They will either abscond or they will go erratically and so they really need a good support system in boarding schools to adhere to their treatment plan.

HCW FGD6, Peer educator

Recommendations to improve access and utilization of social support

To improve viral suppression among YLH, parents/caregivers and healthcare workers proposed interpersonal, clinical, and community-level recommendations that could positively influence access to instrumental, emotional, and informational social support for YLH.

Tailored counseling and HIV education

The participants emphasized the importance of providing age-specific counseling and HIV education for different age groups of YLH. This approach would ensure that healthcare providers can deliver information and support tailored to the varying capacities and understanding of younger and older YLH, thereby enhancing the effectiveness of informational and emotional support.

At the facility, I am requesting that different age sets have their specific day when the health providers can counsel them or provide them with HIV education that suits specific age sets. We have young YLH, who could be 15, 16, 17, and old ones above 20 years. All these YLH have different capacities and understanding, so they should be treated differently.

Caregiver FGD5, Mother

Integrating HIV care in schools

During the discussions, the participants emphasized the importance of integrating antiretroviral therapy (ART) services within school clinics to provide practical assistance and counseling services to school-going YLH.

We should be able to integrate ART services within our schools so that we can take care of the school-going children. This is an age where most of these adolescents have probably had much stigma, and so they may not really open up and be able even to really adhere to their medication. So, if we can have ART refills within those clinics in the schools, if we can be able to offer counseling services within school clinics so that students can also have even support directly coming from the nurse or the health care provider within those schools, then it will be able to directly support these young people who are within the school environment.

HCW FGD2, Clinician

Incentives and motivation

The participants recognized the importance of providing incentives and motivation to address the instrumental support needs of YLH, encouraging them to follow their treatment plans. These incentives included tangible rewards like water bottles, wrist watches, or pillboxes, as well as providing refreshments during clinic visits.

The incentives can also act as a reminder for them to be taking their ARVs as required. I can remember last time at the facility they were given wristwatches and some were given pill boxes.

Caregiver FGD3, Mother

Continuous education for caregivers and YLH

The participants highlighted the necessity of continuous education for caregivers and YLH. They stressed the importance of joint training sessions to ensure both caregivers and YLH stay informed about the evolving aspects of HIV care, fostering better understanding and support within the family unit. This approach also helps YLH realize they are not alone, promoting a sense of community and shared experience.

Caregivers like us, should know that knowledge is something continuous and it changes with time and so we should be ready to always learn new things on how to stay with these children so that they can have some comfort from us. The YLH should also be taken for training with their caregivers so that they can also know that if they did 'this and that', then, 'this and that' would happen. You find someone is staying with a child but the child does not understand them well. You find the child understanding an outsider more than them. But you know when caregivers are called in for training, thus, someone and their child, then this child (YLH) will get to know that s/he is not just alone in the HIV world but there are also others like him/her. So, we should have some knowledge that is refreshed all the time. Knowledge is very important.

Caregiver FGD3, Father

Peer support groups

The participants highlighted the significance of organizing peer support groups to address the need for medication adherence and emotional support. Scheduling clinic appointments for all YLH on the same day would allow them to receive peer social support. This would provide them with the opportunity to share their challenges and

positive experiences and learn from each other. Ultimately, this would create a sense of community, reduce feelings of isolation, and reinforce treatment adherence.

We may have them in a meeting where we may have those who have high viral load and those who have already suppressed. Then the suppressed share their best practices, the challenges they passed, and the achievements they made to suppress. At that time, they have their peers known as adolescent champions, sitting with them, sharing his or her success stories, the way he or she also started care and treatment and achieved viral suppression. This encourages the non-suppressed a lot. If you share with them your life experience on how you are living with HIV, it also changes their mode of taking pills, from missing drugs, and missing clinics, to changing their attitudes toward coming to the clinic. Mostly in the meetings, this adolescent champion shares his/her life experience and the best practices to achieve viral suppression.

HCW FGD6, Adherence counselor

DISCUSSION

This is the first study to employ card sorting to explore how social support influences viral suppression among YLH. It examined variations in values and tradeoffs YLH make regarding their social support needs. Specifically, the study focused on how the attributes of – who, what, when, and how – differ between YLH with and without viral suppressions. Interestingly, the study found that preferred social support systems were similar regardless of viral suppression status, indicating that specific viral load levels do not determine the type of support sought by YLH. We also observed that social support was necessary across all age categories, and lack of social support correlated with increased viral loads. Challenges in accessing social support were present from the time YLH learned about their HIV status through to their current ART treatment. Understanding the desired support allows for optimizing targeted support leading to sustained viral suppression and improved health outcomes for YLH.

The need for continuous social support regardless of viral load suppression demonstrates the vital role of the networks in the YLH treatment plan. Consistent support throughout all phases of HIV treatment is fundamental for adequately evaluating YLH's overall health^{26,27} and reinforcing positive behaviours and practices that can maintain low suppression levels²⁸. Confirming previous studies, reliable and stable networks¹⁴ provide essential practical assistance, emotional encouragement, and guidance, which help YLH cope with the challenges associated with their condition^{29,30}. YLH anticipate the support from these networks to enhance treatment adherence, improve viral suppression, and ultimately contribute to better health outcomes and overall well-being^{31–33}. However, gaps in social support systems particularly for YLH in boarding schools led to poor outcomes. Identifying sources of support as YLH transition living environments remains critical.

The complex and diverse social support needs of YLH include the necessity for instrumental, emotional, and informational support to manage their HIV. All groups require these types of support to effectively navigate the challenges associated with their condition. Confirming prior research, these forms of support play a crucial role in

overcoming the challenges with ART treatment that impact the management of YLH viral load status^{31,32}. Providing practical assistance in medication adherence, transportation, and food supply not only prevents missed clinic appointments and skipping doses but also reveals that adequate instrumental support can reduce the likelihood of long drug holidays that would negatively impact viral suppression³⁰. In line with other studies, we found that family involvement^{28,32,34} and peer clubs^{26,35,36} offer a supportive environment where YLH with and without viral suppression openly discuss their struggles and positive experiences respectively. Providing a safe space for dialogue and companionship demonstrates that family involvement and peer clubs serve as a protective shield against emotional distress which has the potential to interfere with viral suppression efforts during the YLH HIV treatment journey. The safe space allows for the sharing of valuable information about HIV treatment, and the provision of emotional support. Empowerment through knowledge about the latest advancements in HIV treatment is crucial not only for YLH's well-being but also for effective HIV management. Previous research reveals that prioritizing empowerment through knowledge can enable YLH to actively engage in their treatment decisions, advocate for themselves within the healthcare system, and stay informed about potential treatment options³⁷. This may allow them to make well-informed decisions regarding their healthcare and treatment³⁰. The support from instrumental, emotional, and informational interventions promotes positive health outcomes¹⁴ and is beneficial to YLH of all ages, as long as they are comprehensive and continuous, regardless of the stage of HIV treatment.

Similar to other studies, we found that insufficient social support hindered medication adherence and directly impacted YLH's overall viral load status³⁸, posing a significant barrier to their positive health outcomes^{30,34}. Inadequate information on ART management²⁸, stigma²⁶, and negative educational environments^{35,36,39} are key challenges for YLH. Systemic issues are particularly pronounced in boarding schools, where inadequate support structures and punitive measures discourage YLH from effectively managing their health^{40,41}. To improve YLH outcomes, there is need for open communication about any HIV-related information, providing sufficient support structures, and implementing policies that cater to students' healthcare requirements.

Our study had some limitations. Achieving a perfect balance of YLH with both high and low viral load levels at recruitment was difficult as some of the YLH with high viral load declined participation. However, data saturation was achieved with the sample size available. The data was collected from YLH living in one largely rural county in Kenya with high HIV prevalence and may not reflect the social support needs of YLH living in other environments.

CONCLUSION

A robust and consistent social support system is crucial for YLH, regardless of their viral suppression levels. Interventions should prioritize a multifaceted approach that addresses their diverse needs across different stages of treatment.

RECOMMENDATION

Implementing age-specific counseling and HIV education sessions, integrating ART services within school clinics, promoting peer support and empowerment, and providing tangible incentives can help improve access and utilization of social support for YLH. These strategies address practical aspects of healthcare delivery and aim to enhance their emotional well-being and knowledge to make appropriate decisions about their treatment options. Ultimately, this will lead to better treatment outcomes and an improved quality of life.

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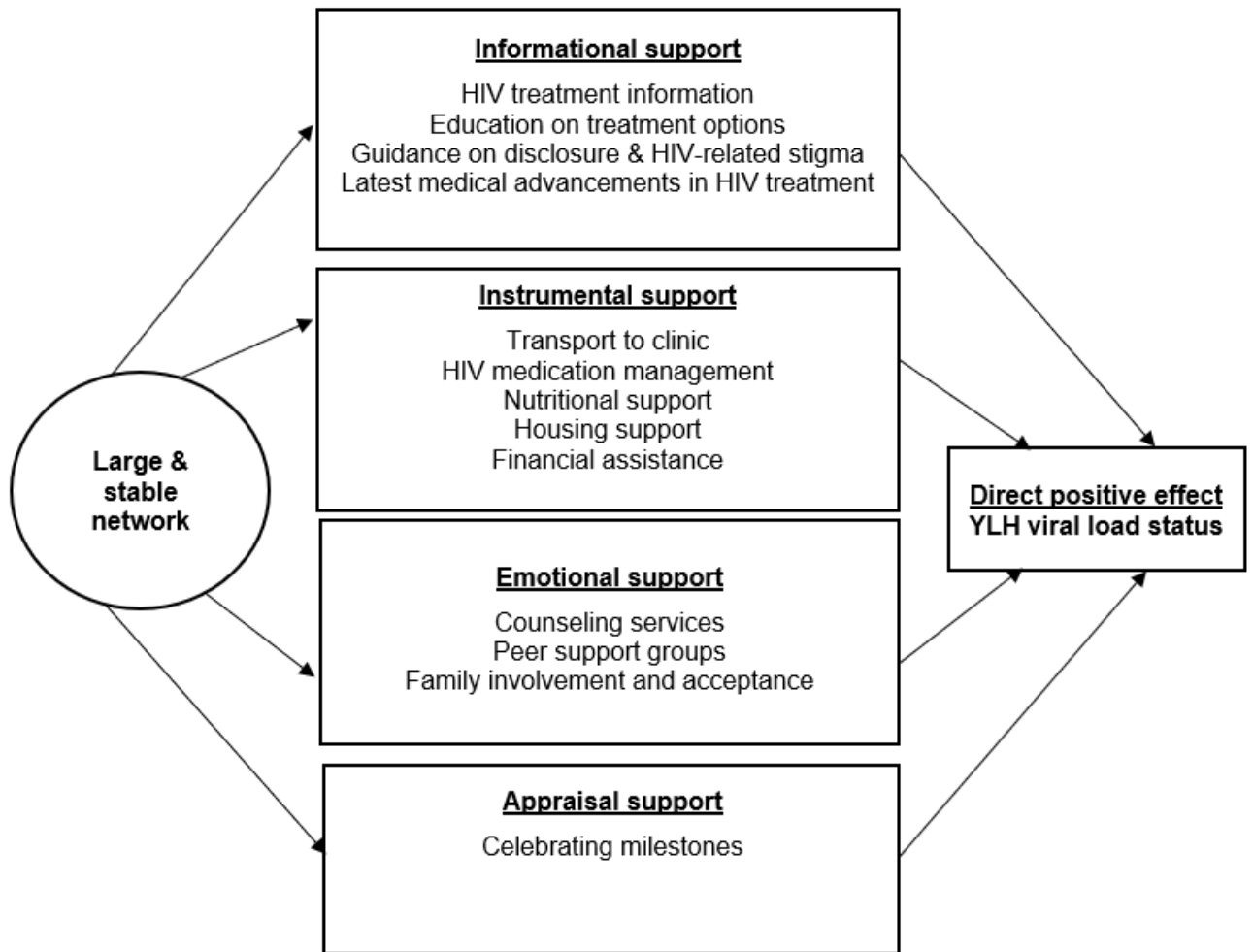
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APPENDIX

Figure 1: Conceptual Framework of the direct positive effect of social support



Adapted from Cohen and Wills Main Effect Model, 1985

Table 2: Characteristics of participants

In-depth interviews			
	High Viral Load (HVL)	Low Detectable Level (LDL)	All Participants
Age Range			
15-18	6 (55%)	5 (45%)	11 (100%)
19-21	2 (20%)	8 (80%)	10 (100%)
22-24	4 (44%)	5 (56%)	9 (100%)
Gender			
Male	5 (42%)	7 (58%)	12 (100%)
Female	7 (39%)	11 (61%)	18 (100%)
Education Level			
Primary	5 (63%)	3 (38%)	8 (100%)
Secondary	7 (35%)	13 (65%)	20 (100%)
College	0	2 (100%)	2 (100%)
Marital status			
Single	8 (35%)	15 (65%)	23 (100%)
Married	3 (50%)	3 (50%)	6 (100%)
Separated	11 (100%)	0	1 (100%)
Focus group discussions			
	Parents/ Caregivers	Healthcare Workers	All Participants
Age Range			
24 -29	2 (40%)	3 (60%)	5 (100%)
30-39	4 (27%)	11 (73%)	15 (100%)
40-49	6 (60%)	4 (40%)	10 (100%)
50-59	5 (100%)	0	5 (100%)
60+	1 (100%)	0	1 (100%)
Gender			
Male	8 (40%)	12 (60%)	20
Female	10 (63%)	6 (38%)	16
Education Level			
Primary	5 (100%)	0	5
Secondary	9 (100%)	0	9
College	4 (18%)	18 (82%)	22
Marital status			
Single	0	6 (100%)	6 (100%)
Married	15 (56%)	12 (44%)	27 (100%)
Separated	1 (100%)	0	1 (100%)
Widow	2 (100%)	0	2 (100%)

Table 3: Results of the YLH card sorting exercises

	Most important	Somewhat important	Not important		Most important	Somewhat important	Not important
WHO				HOW			
Mother	12 (40%)	2 (7%)	0	Medication adherence support	14 (16%)	13 (14%)	0
Father	0	5 (17%)	0	Nutritional support	8 (9%)	11 (10%)	1 (1%)
Grand Mother	6 (20%)	2 (7%)	0	Financial support for transportation and other incentives	10 (11%)	12 (13%)	2 (2%)
Grand Father	0	0	0	Housing support	1 (1%)	2 (2%)	9 (10%)
HCW	8 (27%)	6 (20%)	0	Access to reliable HIV information	11 (12%)	10 (11%)	1 (1%)
Sister	1 (3%)	7 (23%)	0	Education on HIV treatment options	6 (7%)	5 (6%)	0
Brother	0	3 (10%)	1 (3%)	Guidance on disclosure & HIV-related stigma	3 (3%)	4 (4%)	2 (2%)
Aunt	1 (3%)	3 (10%)	0	Information on the latest medical advancements in HIV treatment	9 (10%)	4 (4%)	0
Husband	2 (7%)	1 (3%)	0	Counseling services	7 (8%)	9 (10%)	4 (4%)
Cousin	0	0	1 (3%)	Family involvement in treatment & acceptance	11 (12%)	11 (12%)	2 (2%)
Boyfriend	0	0	14 (47%)	Peer support groups	8 (9%)	8 (9%)	3 (3%)
Girlfriend	0	0	5 (17%)	Celebrating milestones	2 (2%)	1 (1%)	10 (11%)
Teacher	0	1 (3%)	3 (10%)	TOTAL	90 (100%)	90 (100%)	30 (100%)
Peer (casual friend)	0	0	5 (17%)				
Mother-in-law	0	0	1 (3%)				
TOTAL	30 (100%)	30 (100%)	30 (100%)				
WHAT				WHEN			
Instrumental	11 (37%)	10 (33%)	2 (7%)	ART initiation	0	0	13 (43%)
Informational	9 (30%)	7 (23%)	4 (13%)	ART follow-up	8 (27%)	12 (40%)	4 (14%)
Emotional	10 (33%)	9 (30%)	3 (10%)	High VL	16 (53%)	5 (17%)	5 (17%)
Appraisal	0	4 (13%)	21 (70%)	VL monitoring	3 (10%)	8 (26%)	7 (23%)
TOTAL	30 (100%)	30 (100%)	30 (100%)	Viral suppression	3 (10%)	5 (17%)	1 (3%)
				TOTAL	30 (100%)	30 (100%)	30 (100%)

Table 4: Results of the FGD card sorting exercises

	Most important	Somewhat important	Not important
WHO			
Mother	5	1 (17%)	0
Father	0	0	0
Grand Mother	0	1 (17%)	0
Grand Father	0	0	0
HCW	0	1 (17%)	0
Siblings (bro/sis)	0	2 (32%)	0
Aunt	0	0	0
Spouse	1	1 (17%)	0
Cousin	0	0	0
Boy/girlfriend	0	0	6 (100%)
Teacher	0	0	0
Peer (casual friend)	0	0	0
Mother-in-law	0	0	0
	6 (100%)	6 (100%)	6 (100%)

WHAT			
Instrumental	2 (33%)	2 (33%)	1 (17%)
Informational	3 (50%)	0	0
Emotional	1 (17%)	4 (67%)	0
Appraisal	0	0	5 (83%)
TOTAL	6 (100%)	6 (100%)	6(100%)

	Most important	Somewhat important	Not important
HOW			
Medication adherence support	5 (28%)	0	0
Nutritional support	2 (11%)	0	0
Financial support for transportation and other incentives	0	1 (6%)	4 (67%)
Housing support	0	0	0
Access to reliable HIV information	4 (22%)	1(6%)	0
Education on HIV treatment options	0	4 (22%)	0
Guidance on disclosure & HIV-related stigma	3 (17%)	2 (11%)	0
Information on the latest medical advancements in HIV treatment	0	0	0
Counseling services	0	4 (22%)	0
Family involvement in treatment & acceptance	2 (11%)	4 (22%)	0
Peer support groups	2 (11%)	2 (11%)	0
Celebrating milestones	0	0	2 (33%)
TOTALS	18 (100%)	18 (100%)	6 (100%)

WHEN			
ART initiation	6 (100%)	6 (100%)	0
ART follow-up	0	0	0
High VL	0	0	0
VL monitoring	0	0	1 (17%)
Viral suppression	0	0	5 (83%)
TOTAL	6 (100%)	6 (100%)	6 (100%)

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