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Full Length Research Paper

‘Now that you have eaten, it is time for drugs’: Adherence Support Systems among Adolescents on Second-line Antiretroviral Therapy in Rural Western Kenya

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Abstract

The initiation of antiretroviral therapy (ART) was a significant milestone in the care and management of HIV; however, adolescents living with HIV (ALHIV) on ART were the only sub-population that registered a 50% increase in deaths after initiating ART due to sub-optimal adherence. Despite reduced therapeutic options, higher risk of repeated treatment failure, and the cost implications for the healthcare system, there needed to be more information focusing on optimal adherence support. This study explored how existing psychosocial support systems promoted adherence among 15-19-year-old ALHIV. The study used social ecological theory to explore the interplay between available resources, health habits, and respondents' lifestyles. Focused ethnography was employed to collect data from 37 ALHIV on 2nd-line ART. The study administered 37 semi-structured questionnaires, used direct observation, conducted ten in-depth and 13 key informant interviews, and held 3 focused group discussions. Quantitative data were analyzed using descriptive statistics with the aid of SPSS version 20 and presented in tables of frequencies and percentages. Qualitative data was exposed to thematic analysis and presented using descriptions and verbatim quotations. The study findings showed that psychosocial support systems were vital in promoting adherence among ALHIV on ART.

Keywords: ALHIV on second-line ART; Psychosocial; Support; Reminder tools; Adherence.

INTRODUCTION

Adolescents (10-19 years) are disproportionately affected by HIV and AIDS as they transition into adulthood (UNAIDS 2022). One hundred thirty-three thousand four hundred fifty-five adolescents live with HIV in Kenya. There are also 18,004 new infections and 2,797 deaths among adolescents 10-19 years annually. Adherence support for adolescents is necessary to sustain treatment, reduce instances of HIV drug resistance (HIVDR) and promote the achievement of global targets of 90-90-90 for treatment by 2020, and eliminate AIDS as a public health threat by 2030 (UNAIDS,2017). Psychosocial support addresses the ongoing emotional, social, and spiritual concerns of both ALHIV and their caregivers. Psychosocial interventions promote ART adherence among people living with HIV in various contexts. Rajesh et al. (2014) found a strong association between the use of reminder tools and ART adherence. There is a need for further research into the contribution of these factors to adherence as poor ART adherence among ALHIV has been persistent over the years and is still a significant concern, especially following the WHO guidelines on the 'test and treat' strategy and the rising levels of HIVDR in the population.Studies on interventions such as Agbaji and Agaba, 2007; Nachega et al. 2014, Pearson et al., 2007; Sarna et al., 2008, have focused on adult populations, excluding adolescents. Adherence has improved with support groups, positive-living workshops, and buddy services, among other community-based support strategies (Kabore, Bloem, and Etheredge, 2010; Kunutsor et al., 2012). However, there is a dearth of information on whether similar interventions, if applied to ALHIV on ART, would yield results similar to those observed among adults living with HIV.

In addition, other behavioral interventions such as the use of reminder mobile phone text messages (Lester et al., 2010; Pop-Eleches et al., 2011) and directly observed treatment (DOTs) (Idoko et al., 2007; Pearson et al., 2007; Sarna et al., 2008) have also shown positive results concerning adherence to ART among adults living with HIV. However, given that barriers to adherence vary among societies and age categories, the success of adherence improvement interventions may depend on how interventions adapt to the unique challenges in each society or among specific age categories. A more significant percentage of ALHIV on ART in rural contexts may need access to mobile phones or are in school settings that disallow mobile phones. It is unknown whether they may successfully use mobile phone reminders to increase their use and adherence to ART. On the other hand, Ellington et al. (2012) noted that interventions to improve adherence among ALHIV should be targeted both at them and their caregivers. However, disclosure status and levels of HIV stigma within the community have influenced the efficacy of community-based support strategies. High levels of stigma and discrimination for PLHIV are reported continually in rural communities in western Kenya. Thus, it is unclear whether the high levels of stigma have suppressed the emergence and use of community-based initiatives for ALHIV on ART.

Furthermore, the context within which most ALHIV find themselves, such as school set-ups with resultant time constraints, inadequate knowledge, and limited resources, may not promote engagement of ALHIV on ART with support groups in instances where the groups exist. In addition, health-provider-initiated interventions may need help with the healthcare system's challenges, such as a lack of adolescent-friendly health centers, limited personnel, long distances to the health facility, and transport costs, among others (Owuondo, 2015). This study, sort to answer the following research questions:

1. What forms of psychosocial support systems do ALHIV on 2nd line ART have?
2. How do these systems promote adherence to ART among ALHIV on 2nd line ART?

Theoretical Framework

Adherence to ART is a complex phenomenon influenced by the context in which a patient adheres to the prescribed medication and the relationships with family, friends, the community, and other social elements that influence his/her life (Berben et al., 2012). The study employed the Social Ecological Perspective (SEP), which recognizes the intertwined relationship between an individual and their environment. SEP developed out of the work of researchers such as Bronfenbrenner (1979), Mc Leroy (1988), and Stokol (1992, 2003), which identified the core assumptions which underpin SEP (cited in Gombachika et al., 2012). When making lifestyle changes to improve health and reduce risk, it is crucial to consider various factors influencing individual behavior, such as social, institutional, and cultural contexts (Edler et al., 2007).SEP incorporates the concept of interdependence derived from systems theory to understand the dynamic interrelations between people and their environments. Thus, people-environment transactions involve cycles of mutual influence whereby the physical and the social features of settings directly influence their occupants' health. Concurrently, participants in settings modify the healthfulness of their surroundings through their individual and collective actions. SEP, therefore, provided a valuable framework to study the interplay between the various contexts of home, community, healthcare, and school where ALHIV lived.

MATERIALS AND METHODS

This study was part of a more extensive Ph.D. research work that used a focused ethnographic research design typified by short-term field visits, an interest in a specific research question, a researcher with insider or background knowledge of the cultural group, and intensive methods of data collection and recording such as video and audio-taping (Higginbottom, 2013). It was conducted for one year, subdivided into four phases. The study was conducted in Gem sub-County, located in Siaya County, known for highly endemic diseases like HIV and Malaria. (Kenya HIV Estimates, 2015). It is a rural area occupied by the Luo ethnic community where matters concerning adolescent sexuality were traditionally handled very seriously, as exemplified by institutions such as *siwidhe, duol*, and *simba* (Ocholla-Ayayo, 1976). However, social change, formal education, the money economy, and the ravaging effects of HIV and AIDS have altered all these. It is part of the KEMRI/CDC Health and Demographic Surveillance Area (HDSA), which provides comprehensive population-based data on various health indicators and population Knowledge and beliefs at the individual and household level (Odhiambo et al., 2012).

The study targeted ALHIV on second-line ART aged 15-19 years enrolled in the 29 public patient support centers (PSCs) in Gem sub-County.Male and female ALHIV formed the study population. The study also engaged caregivers of ALHIV and key informants. The unit of analysis was ALHIV on second-line ART.

No direct records indicated the number of ALHIV on second-line ART aged 15-19 years. At the sub-County and PSC levels, reporting is done according to 0-10, 10-19, 18, and above age categories with no specifications on the ART line. This necessitated a reconnaissance study in order to arrive at the study population. The study area had 29 PSCs divided into six administrative units/wards. To choose one PSC, a random number selection process was implemented. These PSCs were the focal points for recruiting ALHIV on second-line ART for the study. The study included all 37 ALHIV on second-line ART as respondents due to the low number of participants from the sampled PSCs.

The study administered semi-structured questionnaires to 37 ALHIV within the 6 PSCs. This was translated into the local language *(dholuo)* to ensure respondents understood the questions.

Thirteen key informants were purposively selected based on their knowledge of ART adherence-related issues and their regular interactions at the PSC with respondents. These included six adherence counselors, six peer educators, and the adherence and retention officer from Centre for Health Solutions (CHS), which plays a supervisory role in all the PSCs within the sub-County. The study recruited adherence counselors and peer educators from each of the sampled PSCs. Key informant interviews were conducted using a key informant interview guide. The interviews lasted 30-40 minutes, were conducted in both English and *Luo*, and were audio recorded.

During visits to the homesteads of respondents and caregivers for in-depth interviewing, I observed such things as the type of house and household items; the way the respondents spoke about their issues, for instance, whether they were free, tensed, whether they spoke in whispers or were audible without probing to speak slightly louder, whether the respondents were influenced by the arrival of a family member or not, and if this made the respondent either reduce the volume of their voice or continued as previously; whether there were visible opportunistic infections; hospital cards to ascertain if they had missed or kept all appointments promptly. In addition, other non-verbal cues were also observed. At the PSC, I observed the presence of wall hangings, posters, and other ART adherence-promoting mechanisms; the existence of adolescent-friendly services; the duration the ALHIV took to get a pill refill; the process followed to get the pill refill; the length of adherence counseling sessions; how patient confidentiality and privacy were maintained; how ARVs were dispensed, packaged and carried home and the length of the Operation Triple Zero (OTZ) campaign sessions. During the discussion, I used an observation checklist to note the non-verbal behavior of the participants. I also combined this with direct observation during the focus group discussions.

The study used an in-depth interview guide with ten (seven male and three female) ALHIV that were purposively selected to obtain detailed information on the topic of study. The study also used another in-depth interview guide to conduct caregiver interviews. The study engaged ten (eight females and two males) purposively selected caregivers of the respondents to understand the intricacies of caregiving. The respondents were interviewed in their homes for a more thorough and detailed discussion.

Focus group discussions (FGDs) were used to help the study obtain more insight into the themes that arose during the administration of the other data collection instruments. The study conducted an FGD with eight male respondents in *the Gongo* health center and another FGD with eight female respondents in *the Wagai* dispensary. The FGDs were conducted within the PSC to ensure privacy and that discussants did not feel exposed to other community members, most of whom were unaware of the discussants' ART status. The dates for conducting the FGDs also coincided with most respondents' appointment dates/clinical visits to avoid unnecessary inconveniences. Both FGDs were conducted in the morning between 10:30 a.m. and 12:30 p.m., immediately after they had finished the process of pill refill or other clinical engagements. The third FGD was conducted with 8 (six female and two male) caregivers. This, too, was done in *the Gongo* health center. It included five social and three biological caregivers; among them, only one female biological caregiver was not on ART. In addition, four caregivers were of male, and four caregivers of female respondents. This FGD was conducted in the afternoon, from 2:00 p.m. to 4:00 p.m., because during its preparation, the caregivers intimated that they were engaged in other activities in the morning hours and would be primarily available in the afternoon. It was also conducted within the PSC to ensure privacy. The researcher moderated the discussions while a research assistant took creamy notes. The discussions were also voice recorded. The study used two FGD guides, one with respondents and another with caregivers.

The study also utilized secondary sources of information relevant to the study topic. I obtained relevant literature from the library, specifically articles and journals, various books, including Google books, research reports, and website materials. Secondary data were used to supplement primary data and to put the discussion on the study objectives in context.

Data Analysis and Presentation

Data interpretation began while the fieldwork was in progress. After each research phase, the researcher analyzed the gathered information and identified recurring themes that influenced the direction of the research. Once the fieldwork was over, the researcher coded the data from the semi-structured questionnaire administered to ALHIV and subjected it to Statistical Package for Social Science (SPSS version 20) to establish frequencies and percentages. Cross-tabulations were done, and it enabled the researcher to identify appropriate relationships between the sets of qualitative data. Transcription, translation, and coding of voice-recorded data from in-depth interviews and FGDs followed. The process led to emerging themes and patterns that the researcher used to establish explanations and deductions. Quantitative data were presented using tables that offered frequencies and percentages and relationships between different variables and adherence to ART. Qualitative data were presented using descriptive reports and verbatim quotations.

Ethical Considerations

The study was approved by Maseno University Ethics and Review Committee and permission from the Centre for Health Solutions (CHS), as it has a supervisory role over all the public PSCs in Gem Sub-County, was also obtained. The researcher also sought permission from the PSC in charge of the 6 sampled PSCs for the study. The study used adherence counselors and peer educators within the PSCs as points of initial contact with ALHIV and their caregivers. The researcher sought written informed consent from caregivers who accompanied the ALHIV to the PSC and assent from ALHIV. Before acquiring informed consent, I thoroughly explained the study to the caregivers and the ALHIV. The Kenya National Voluntary Counseling and Testing guidelines allow mature minors to consent. Thus, the mature minor that was part of the study respondents gave informed consent on her behalf. The study did not cause any harm to the participants, whether it be physical, psychological, or otherwise. The study, however, ensured the comfort, confidentiality, and privacy of the data collection methods and provided logistical support to study participants to and from the PSC while conducting research. Participants in the study were guaranteed that their responses would be kept confidential and not shared in any manner that would compromise their privacy.

RESULTS

Theme 1:**Family and Community-based Psychosocial Support Systems Promoting Adherence to ART**

Sub-theme 1: Human and non-human reminder tools

Adolescents living with HIV, just like their age-mates, depend on familial and community networks for emotional support in times of need. When asked how their families helped them with their adherence to ART while administering the semi-structured questionnaire, the study's findings showed that the main form of support ALHIV (59.4%) got from their families was getting a reminder that it was time to take drugs.

All ALHIV (10) respondents to in-depth interviews reported receiving a reminder to take their drugs. One ALHIV narrated that:

Once we have just eaten, my mother says that now that you have eaten and are full, it is time for drugs. She ensures I take the drugs while she is watching to ensure I have taken them (IDI with a female ALHIV).

It was also unanimously reported during the FGDs, both for ALHIV and their caregivers, that family members, especially those within the same household, ensured that they reminded ALHIV to take their drugs. This was achieved through the various reminder tools used, as shown in Table 4. There were, however, 6 ALHIV who did not report having any form of a reminder tool, nor did they have anyone reminding them to take their drugs within the households where they lived.

A small proportion of ALHIV reported being reminded to eat well (19%), while 8.1% were not given much work as forms of psychosocial support they received from their families. During an in-depth interview, a female ALHIV reported that her grandmother gave her a bigger *ugali* and more eggs to eat. She almost always had *'ponge' (mandazi),* especially on Sundays, for tea in the morning. Similarly, one male ALHIV during an FGD reiterated that:

You need to eat well, eat *ugali* properly. So even if it is with vegetables, I eat them well because it increases blood in my body; even with small fish, I also eat well, after which I take water. My grandmother has greatly assisted me (Male ALHIV: FGD discussant).

Sub-theme 2: Sufficient quality food

Caregivers were also keen to avoid food staffs that would counter the strength of the ARVs. While conduct-

Table 3: Family-based Psychosocial Support Promoting Adherence to ART.

		Frequency	Percent
	I am not given much work	3	8.1
	I eat well	7	19.0
	My family reminds me time to take drugs	22	59.4
	No one is concerned	5	13.5
	Total	37	100.0

Table 4: Reminder Tools for Adherence to ART.

Reminder Tools	**Frequency**	**Percent**
The alarm on the ALHIV phone	6	16.2
The alarm on the caregiver's phone	13	35.2
None	6	16.2
Radio news	6	16.2
Sibling	3	8.1
Verbally by caregiver	2	5.4
Wristwatch	1	2.7
Total	**37**	**100.0**

ing in-depth interviews with caregivers, only 1(male caregiver) out of 10 reported having problems providing for the nutritional needs of the ALHIV under his care.

For example, one female caregiver of a male ALHIV during an in-depth interview narrated that:

I stopped cooking with *saumu* because I was told while we were still staying in Nairobi that it reduces the strength of ARVs. I also ensure there is good food and that tea is always available in the thermos flask because he gets hungry most of the time. You know, even when we go to the farm, I allow him to go back home early. I also do not give him strenuous work; we were told that they have little energy. When they go to the river to fetch water, my son, his age mate, makes four trips while he only has two (IDI with a caregiver).

Similarly, another female caregiver of a male ALHIV reported during an FGD that:

I have to ensure that he eats well; I give him much compared to my other grandchildren; when I cook eggs, we have been told *ni ok gi chiem size wa, gichemo mangey* (they do not eat our size, they eat a lot). *Kata gima imadho go chaye amiye maber* (I give him an excellent 'escort' for his tea) to ensure he is healthy to avoid him being weak (IDI with a female caregiver)

In addition, one male, ALHIV, during an in-depth interview, reported that he still eats well even when he goes to school. He continued to narrate that:

In school, those of us on different types of medications do not queue for meals; we have special plates that give us more food when the cook sees them. In class, we are also not assigned strenuous duties; for example, when the class has been punished to slash the compound, we are exempted (IDI with a male ALHIV).

Sub-theme 3: Emotional Support

Regarding emotional concerns, the study sought out who among their family members the ALHIV confided in whenever they had emotional issues and why they chose that particular family member(s). Results from the semi-structured questionnaire interviews indicated that among all (8) ALHIV whose parents were alive, the mother was the one they confided in as opposed to the father. This finding was factual even for male ALHIV. Reasons given by ALHIV were that mothers were more accessible than fathers; mothers were close and more understanding than fathers. ALHIV were also most likely to confide in whoever disclosed their HIV status to them, whether directly or indirectly, assisted by the healthcare provider. After HIV disclosure, the caregivers became treatment supporters (TS) for ALHIV as they initiated ART.

In addition, there were instances where ALHIV reported that they had no choice but to confide in whomever they lived with because these were the people who cared for their needs. However, ALHIV reiterated that in such instances, they did not feel free to discuss some of their concerns with such family members because of the age difference. As a result, they opted to confide in their friends. During an in-depth interview, one male ALHIV narrated:-

I have a friend in class seven like me, but in a different school; he is also my neighbor. Because he is the one I share my issues, I am planning to convince my grandmother to transfer me to his school so that we can have more time together (IDI with a male ALHIV).

On the contrary, five ALHIV reported no one was concerned with their ART adherence-related activities. Data analysis revealed that these five ALHIV were among six who reported having no reminder tool and those who exhibited poor adherence. This follows to show that inadequate caregiver support contributed to poor adherence among ALHIV. The researcher met one male, ALHIV, who was out of school and had a different experience regarding family support. During an in-depth interview, he reported that he just kept to himself since no one liked him because he was born out of wedlock, and later, his mother got married and took him along. When asked why he did not confide in his mother, he said:-

My mother took an inheritor after her husband died, and now they are too busy. They do not even see that I am around. I want to leave, maybe look for work in someone's homestead, even as a herdsboy, to get out of her way (IDI with a male ALHIV).

Sub-theme 4: Community-based Support Groups

The study sought to determine whether there were any support groups for ALHIV within their community. All (37) ALHIV who responded to the semi-structured questionnaire reported none. The primary reason for the lack of support groups within the communities was fear of stigma and discrimination. It was reported that because older PLHIV were not free to disclose their status, it was difficult for ALHIV to do the same. This sentiment was also alluded to during an FGD with caregivers of ALHIV. One female caregiver reported that having a support group would expose the status of ALHIV to the community. She did not see why that should be so because even adults had hidden their status from the public. Similarly, one female ALHIV reiterated during an FGD that:-

Once people know you take drugs, you become the topic of gossip whenever you pass, especially if you go to the market in the evening and those market women see you, they will talk about you. Furthermore, sometimes they laugh as you pass, which is very frustrating (Female ALHIV: FGD discussant).

Another male ALHIV, during an FGD, reported that *people would see thema sunclean and reject them.*

Theme 2: Heath Care Provider-based Psychosocial Support Systems Promoting Adherence to ART

Sub-theme 1: Pill Refill

Every ALHIV on ART must be enrolled in a PSC to facilitate HIV care and management. According to one key informant, all PSC patients are advised to report to their respective PSCs whenever they have any ailments before seeking treatment elsewhere. Apart from pill (ARVs) refills, the study sought to establish psychosocial support for ALHIV accessed from the PSC.

Apart from pill refills, 54.1% of ALHIV reported a series of teachings on caring for themselves, especially ensuring that they took their drugs as prescribed. Similarly, 32.4% of ALHIV also reported being given nutritional support in milk, bread, and flour for porridge. Caregivers of ALHIV also reported attending teaching sessions at the PSC, where they discussed how to support those under their care. During a key informant interview, it was confirmed that the PSC organized sensitization sessions for caregivers of ALHIV. However, the key informant quickly reiterated that difficult caregivers never attended such sessions, always claiming they were busy in one place or another. During key informant interviews, it was reported that:

Most issues are fear and self-stigmatization. It is more helpful when the caregiver is free with her status as it promotes acceptance and helps the ALHIV fight peer stigma. Some caregivers are complicated, affecting the ALHIV (KII with adherence counselor).

Sub-theme 2: The OTZ support group

When asked whether there were support groups at the PSC, all (37) ALHIV reported in the affirmative. Unfortunately, there were no support groups established by ALHIV themselves. At the time of conducting this research, the only form of psychosocial support group evident in all the sampled PSCs was provided through the Operation Triple Zero (OTZ) campaign held once every month. This is what ALHIV referred to as a support group. It had three main objectives that embodied the PSCs’ goals in relation to optimal adherence among ALHIV. OTZ stands for zero new infections, zero missed appointments, and zero deaths. It was also customized to mean zero missed drugs and zero viral loads to motivate ALHIV to adhere to their ART. Through the funding of OTZ campaigns, ALHIV received milk (500 ml) and bread/biscuits/*mandazi* whenever they met at the PSC. ALHIV also wore T-shirts with the CHS logo and labels such as 'I am a Hero' and 'My ZEROs my LIFE' to motivate ALHIV not to miss OTZ campaign sessions. It is also under OTZ campaigns that some ALHIV had attended workshops and World AIDS Day celebrations. In its guidelines, however, after age 19, ALHIV has to exit the OTZ support group. During key informant interviews, one key informant was worried that those ALHIV who had to exit might become lonely and lack social support hence rescinding back the gains made while in the group. During an in-depth interview, one male ALHIV, who was 19 years old when the study began and had to exit because he had turned 20 years by the time the study was winding up, shared his fears resulting from having to exit OTZ. He narrated: *I have been used to going to the PSC every first Saturday of the month when we meet at OTZ, but now I can no longer go.*

The following is an excerpt from the in-depth interview:

Researcher: Do you miss OTZ?

ALHIV: A lot; we used to share our experiences, and it was easy to ask the sister/nurse a question without feeling guilty. You know there are some questions that you cannot ask at home, but at the OTZ, we were encouraged to talk. Even I miss how sister/nurse narrated stories to motivate us to open up and share.

Researcher: So, what do you intend to do now?

ALHIV: I have been thinking, what if I tell my sister/nurse to make me an OTZ champion?

Researcher: Who is an OTZ champion?

ALHIV: I assume the one who has gone through the OTZ and has exited like myself.

Researcher: How will being an OTZ champion support your ART adherence?

ALHIV: At least I will still be going like others.

The study was also interested in discovering what happened whenever ALHIV met for the OTZ campaign sessions. This was the principal forum used by the PSC to offer psychosocial support that would help promote adherence among ALHIV. After the researcher attended several such sessions in the sampled PSCs, it was evident that some script was being followed by the healthcare providers whenever there was an OTZ session. The OTZ sessions began with gospel songs reiterating the situation ALHIV had found themselves in and were beneficial towards giving/restoring hope in life. For example, songs such as:-

Ka an gi Yesu ok ayiengini (×2) [If I have Jesus, I am strong (×2)]
Achalo gi yath motwi e aora [Am like a tree planted by the riverside]
Ok ayiengini [I am strong]
And
Nyasaye wuora in ng'a manadi (×4) [God my father, how mysterious are you (×4)]
Ogola piny oketa diere [You picked me from the ground and put me in the middle]
Ogola diere oketa malo [You removed me from the middle and placed me at the top]
Nyasaye wuora in ng'a manadi [God my father, how mysterious are you]

These songs, sung while clapping hands and dancing, promoted happiness among ALHIV. The purpose of the songs was to give ALHIV hope that a benevolent God in heaven understood their difficulties and actively worked to improve their situations. After singing, prayers followed with each ALHIV encouraged to pray for themselves and tell God their desires. The sessions followed with discussions that exposed viral load (VL) test results of ALHIV with good adherence, that is, those with the least VL. They were clapped for and were used as examples to encourage others with high VL to improve their adherence. It was during such sessions that I witnessed how emotionally affected ALHIV became when the key informant took stock of the progress of the year 2018. He mentioned that three ALHIV had passed on during the year, and the leading cause of their deaths was not taking their drugs as instructed. Among the three ALHIV who died, one stopped taking drugs because he was being denied food by his step-mother whom he was staying; another was suspected to have committed suicide though he had persistent high VL despite much counseling, while the third ALHIV had stopped taking drugs after her mother passed on. No one was willing to be engaged by the PSC to do DOT. Such sessions gave ALHIV moments to reflect on their lives, especially when they bowed for a moment of silence in respect for their fallen age mates and made necessary adjustments concerning their ART adherence.

The study sought to establish whether belonging to a support group influenced adherence among ALHIV. A majority (94.6%) of ALHIV who responded to the semi-structured questionnaire reported that being part of the OTZ campaign encouraged them to take their drugs. It made them feel happy seeing their fellow ALHIV doing well too. Other (88.4%) ALHIV reiterated that the OTZ sessions helped them realize the need to keep time and avoid delaying taking their drugs. They also allowed them to visualize the consequences of not taking drugs. *It encourages and motivates me to soldier on despite my status, especially when I see my fellow ALHIV having similar problems like mine and even others having worse ones* was also a response given by a female ALHIV during an in-depth interview. Another male ALHIV, during an FGD, reported that such sessions gave them an opportunity to seek relevant information concerning their drugs.

There was, however, one particular male ALHIV aged 17 years whom I encountered during one of the OTZ sessions who reported that OTZ sessions had not helped him much, but on probing, he said:-

I rarely go because I come from far and I usually have no transport fare. At times I do not have the time. I live with my grandmother, who is blind, and I have to look for money, buy food for us, and pay some at school (In-depth interview with male ALHIV).

The following is an excerpt from the interview:

Researcher: Why don't you consider going to a PSC near you?

ALHIV: People will know I take drugs and gossip about me.

Researcher: What about this T-shirt you are wearing? Don't they ask where you got it from and what 'I am a Hero' means?

ALHIV: I do not wear this T-shirt from home. I carry it in my bag and change once I arrive at the hospital.

In addition to the OTZ forums as forms of psychosocial support for ALHIV, I also observed charts hung on the walls of the PSC that had information relating to ART. For example, one particular chart had pictures on how to take drugs well. However, at its end, it also said: - 'If not, you become sick.'

Sub-theme 3: Other desired forms of support

The study inquired whether there were any other support mechanisms that the ALHIV would suggest to the PSC to promote adherence to ART. The main suggestion ALHIV gave was that *there should be other forms of support, not just advice and information.* For instance, male ALHIV during an FGD said they needed economic support, especially those who were in school and orphaned. Some needed clothes and transport fare whenever they were to go to the PSC either for pill refills, VL tests, and OTZ sessions, and more milk and maybe food should also be incorporated in the support from the health care provider. During an FGD with female ALHIV, there was one discussant who had permissive and 'quite reckless' sexual undertones; for instance, when discussing if they had boyfriends or lovers, she said: *I have many lovers, I have no business with boyfriends who have no money to give me but want my body.* The researcher noted and afterward inquired from the key-informant reasons behind such an attitude. Unfortunately, the key informant reported that this female ALHIV had become sexually reckless in providing for her ailing mother and younger siblings. *She has become a village prostitute, and I am worried she may not be using condoms because I have never seen her come for some from the hospital, and I am sure she has no money to buy condoms,* narrated the key informant. This indicates that other forms of support were necessary for ALHIV to help when caregivers could not continue providing for their needs.

Other suggestions made by ALHIV included trips to other PSCs to see how their counterparts were doing and relevant books to read concerning their health. Those ALHIV who came from outlying areas also suggested that *the doctors try and come early to finish early, giving them ample time to trek back home.* Finally, some ALHIV felt that the PSC should increase seats because whenever there were many patients at the center, they had to stand for long hours. When asked how these suggestions would promote adherence to ART, male ALHIV during an FGD reiterated that apart from making them not miss appointments and delay in taking their drugs, it would encourage those who had stopped using drugs to start again and thus reduce deaths of ALHIV.

DISCUSSION

It is evident from the presented narratives that family members, especially when full disclosure had been done, played a crucial role in supporting ALHIV with adherence. Caregivers were interested in both the quality of food and its quantity to ensure maximum growth among ALHIV under their care. Caregivers were cognizant that ALHIV needed not just to be healthy but also to 'look healthy' so as not to attract the villagers' attention. This concern accrues from the initial scenarios of people who were ailing from HIV and AIDS, as they looked thin and 'sickly' when ART had not been initiated. This study finding is in line with a study conducted in Zambia by FHI 360 (2014), which reported that over half of ALHIV surveyed mentioned that family members reminded them to take their ARVs. The concern of the study, however, revolves around persistent poor adherence and deaths reported among ALHIV even after initiating ART. Even though narratives show that ALHIV were constantly reminded to take drugs and caregivers ensured that they eat well, SEP espouses that the effectiveness of health promotion efforts depends on the interplay between environmental resources available in an area and particular health habits and lifestyles of the people who occupy that area (Stokol, 2003). This implies, therefore, that caregivers could lack consciousness of the interplay between adequate food of good quality and other socio-cultural and demographic factors such as gender, sexual debut, and ART knowledge and how these influence adherence. It could be argued, thus, that ALHIV and their caregivers have concentrated on other factors at the expense of an understanding of the relationship these factors have with one another and their subsequent influence on adherence.

ALHIV, like their age mates, experienced emotional issues, as exemplified by the study findings, and in almost all instances, had someone whom they trusted and could confide in. Emotional issues, such as the onset of sexuality (wet dreams) and sexual relationships, were significant concerns that caregivers were not sensitive to. This created a vacuum that friends filled. Friends and peers have previously been reported to form a more considerable proportion of confidants among ALHIV. For instance, among a sample of South African adolescents, those with extensive supportive networks among relatives and peers appeared to cope better with psychosocial challenges, with caregivers playing an essential role in facilitating ART adherence (Adejumo et al., 2015). Kabuji et al. (2014) have shown that family environments are crucial for care for ALHIV. In addition, SEP espouses that the interrelatedness of the microsystem and the mesosystem influenced whether one achieved desired health outcomes (Gombachika et al., 2012)

Evidence has shown that the fear of stigma and discrimination (also rejection) among ALHIV and their caregivers hindered the emergence of support groups within their communities. The study confirms the high levels of stigma and discrimination against PLHWA reported by the Siaya County Development Plan (2016) (County government of Siaya, 2016), despite several campaigns on the ground and in the media against stigma and discrimination meted out on PLWHA. This, as evidence has shown, has hindered the emergence of support groups for ALHIV within the study area, thus denying them the benefits that accrue from engagement with support groups reported by studies such as Nyandiko et al. (2006); Abel, (2007) and Ellington, et al. (2012) which have reported the efficacy of support groups in promoting adherence. This may, therefore, contribute to the persistent poor adherence among ALHIV reported by key informants. Efforts towards reducing stigma and discrimination should consider initiating support groups within communities and working with these groups to promote acceptance and enhance psychosocial support for ALHIV.

In addition, individual behavior is influenced by factors at different levels. The macro system, according to SEP, is the domain where the societal, cultural, and economic structures reside. According to Cushman (1990), culture at this level infuses individuals to shape them and how they conceive of themselves and the world around them, how they see others, and how they make choices that influence when, how and with whom they spend their time. Thus analyses of health promotion mechanisms, such as the sensitization sessions at the PSCs, should be sensitive to the lived experiences of both ALHIV and their caregivers to accrue maximum benefit. Therefore, as much as this finding is in line with evidence presented previously by Ellington et al. (2012), who noted that interventions to improve adherence among ALHIV on ART should be targeted both at them and their caregivers, it is important for interventions to address the multidimensional and complex nature of human environments. In addition, even though other studies have reported that caregivers are busy with the provision for the basic needs of the family (Alber, 2004), this study did not elucidate work as the reason behind some caregivers missing PSC appointments. In addition, it was evident that the social and economic forces that have shaped the AIDS epidemic over the years are, in every sense, the same forces shaping ART adherence. Despite massive campaigns and intervention strategies, social forces such as poverty, stigma, and discrimination still influence ART adherence among different age groups, ALHIV included.

Psychosocial support embodies a myriad of initiatives. In this case, it entailed providing a conducive environment for ALHIV to share matters concerning them and learn from one another within the healthcare setting. As Edler et al. (2007) report, individual behavior is influenced by factors at different levels; thus, initiatives geared toward health promotion should give greater attention to people-environment relations. Due to the fact that there were no support groups in the communities where ALHIV lived and the high levels of stigma and discrimination, having an opportunity at the OTZ campaigns thus proved to be vital in promoting ART adherence-related activities.From these study findings and as FHI 360 (2014) reported, 94.6% of ALHIV on ART enjoyed being part of support groups organized by health care providers for various reasons such as liking and feeling comfortable around the clinic staff, enjoying having social interactions with other ALHIV; hearing others' stories and encouraging one another and also engaging in group activities such as sports and outings. In addition, considering the absence of support groups for ALHIV in the communities, having an opportunity to experience oneness at the PSC was highly cherished. Improvement in adherence has been reported with support groups and positive-living workshops among adult populations living with HIV (Kabore, Bloem, and Etheredge, 2010; Kunutsor et al., 2012). However, 43% of ALHIV that the study engaged still exhibited poor ART adherence despite attending OTZ campaigns. Consequently, there was a need for the health care providers, particularly the PSCs implementing OTZ, to explore the missing link and modify this psychosocial support in order to achieve its intended objectives.

The study also espoused other barriers to adherence that were not necessarily related to adolescence as a developmental stage, such as transport costs to access the PSC. These were structural within the mesosystem, and as SEP espouses, social structures such as work, informal and formal social networks, and communication systems influence how individuals make choices in their everyday life (Berben et al., 2012). Furthermore, the study also noted that due to the fear of stigma, there were cases of ALHIV enrolling in PSC very far away from their villages to avoid being seen by those who could recognize them. This is what brought about constraints such as lack of transport fare. In addition, the lack of support groups for ALHIV within the communities has worked against any efforts to reduce stigma and discrimination. However, a myriad of studies that have reported structural barriers such as the cost of transportation to health facilities has been conducted among adults living with HIV neglecting ALHIV who may also face such barriers as the study found (Rosen et al., 2007; Ssewaya, 2011; Odhiambo, 2016).

The study concluded that medication adherence is a complex phenomenon influenced by the interplay between the context in which the patient was expected to adhere and the relationships with family, friends, and the community. When the context of adherence is unfavorable, then speaking about adherence becomes untenable. Efforts towards promoting adherence among ALHIV must thus ensure that other facets of the contexts within which ALHIV live are addressed, especially situations that have arisen due to orphanhood statuses and the inability of primary caregivers to provide for ALHIV under their care adequately. Secondly, given the HIV drug resistance alert issued by WHO in July 2017 in highly endemic zones, the test and treat strategy and the guideline to shift patients to second-line ART at the slightest sign of failure of first-line ART, psychosocial support systems, both from family and health care providers proved to be vital in promoting adherence among ALHIV. Caregivers, despite facing many challenges, such as having to provide extra food servings to ALHIV, were aware that they needed to encourage those under their care to take drugs as prescribed. Similarly, the PSC staff ensured that apart from medication, they instilled hope for the future among ALHIV to motivate them to continue their lifelong treatment regimen.

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