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Exploring Caregiver-Teen-Communication on Adherence to Antiretroviral Therapy among Adolescents Living With HIV in Gem Sub-County, Western Kenya

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Abstract:

Globally, adolescent currently the only age group in which AIDS-related deaths are not decreasing, even among those who have initiated ART. Similarly, low treatment adherence and high treatment failure have also been reported among adolescents. Coupled with low levels of comprehensive and correct HIV knowledge, it is important to understand the interplay between the lived situations of adolescents living with HIV (ALHIV) and ART adherence in order to promote well-being. This study explored communication between ALHIV 15-19 years and their caregivers on ART adherence related issues. Communication about sexual health has been shown to have a protective influence on behaviour. Results showed that there was sufficient communication between ALHIV and their caregivers though with very limited content on ART adherence-related issues.

Keywords: Caregiver-Teen-Communication (CTC), People living with HIV, Luo community, Rural, Siaya County

1. Introduction

In 2018, an estimated 250,000 adolescents aged 10-19 years were newly infected with HIV worldwide, with nearly 80% in Sub Saharan Africa (SSA) (UNAIDS, 2018). In Kenya, annual new HIV infection estimates among adolescents aged 10-19 was 8,200(2,400-15,900) with Siaya County accounting for 890 (NACC, 2018). Despite provision of ART adolescent is currently the only age group in which AIDS-related deaths are not decreasing (UNAIDS, 2017; 2018). In Kenya, annual AIDS related deaths among ALHIV were estimated at 2,100(1,200-3,200) with Siaya County registering 158 (NACC, 2018). Adolescents are thus a key population for HIV prevention and management, first because it is during this stage of development that sexual behaviors are generally initiated and risk patterns established (Soon, et al., 2013). Second, because they feed into other HIV related programs for adults such as Prevention of Mother to Child Transmission (PMTCT) (UNICEF, 2016).

It is important to understand the interplay between the lived situations of ALHIV and adherence to ART in order to sustain the benefits already achieved by such programs. Treatment adherence among adolescents, however, is generally lower and treatment failure rates are comparatively higher than in other age groups (UNAIDS 2017). It has also been reported previously that ALHIV who understand what antiretroviral drugs they are on and how the ARVs work and common side effects are in a better position to take care of their health (UNICEF, 2016; Yang Yu, et al., 2018). According to UNICEF (2016), HIV knowledge is very low in some settings in the Asian Pacific and many ALHIV do not know the name of their treatment regimen. In most countries with generalised epidemics, less than half of adolescent boys and girls aged 15-19 years have a basic understanding of HIV (Idele, et al., 2014). In SSA for instance, only 26% of adolescent girls aged 15-19 years and 36% of adolescent boys of the same age have a comprehensive and correct knowledge of HIV against the WHO recommended level of 85% (Idele, et al., 2017). These disparities among adolescent boys and girls have been linked to gender, education, household wealth and place of residence. For instance, adolescent boys and girls in poor households and residing in rural areas are less likely to have comprehensive and correct HIV knowledge (Idele, et al., 2014). The Kenya Demographic and Health Survey (KDHS) of 2014 reported a comprehensive and correct HIV knowledge level of 52% among adolescents, which is also minimal owing to the high rates of new infections being reported. There could be a problem with the way HIV and AIDS knowledge trickles down to adolescents. For example, various strategies geared towards sensitization and awareness creation have targeted PLHIV who are parents/guardian of perinatally-infected adolescents (PIAs) with an expectation that this knowledge would trickle down to their children including the adolescents (Birungi, et al., 2011). Information, however, on whether adherence-related knowledge forms part of discussions between ALHIV and their caregivers as is envisaged is nascent. Previously, the taboo nature of sexuality discussions between adults, in particular parents and young people, ensured that grandparents were instrumental for impacting the necessary knowledge for sexual relationships (Amuyunzu-Nyamongo, et al., 2005). The traditional community and kinship structures

have however been eroded by increased strain orchestrated by forces driving social change and the HIV and AIDS epidemic (UNICEF, 2016). It is therefore, not known if and how parents/caregivers share with their adolescents/teens issues related to ART adherence. Furthermore, limited studies have explored what exactly constitutes sharing information, more so, on adherence related matters between ALHIV and their caregivers and have only provided a general assessment of that information without offering data on the specific topics discussed. This paper (as part of a larger study on socio-cultural and demographic factors influencing adherence among ALHIV on second-line ART in Western Kenya) endeavors to explore Caregiver-Teen-Communications (CTCs) on ART adherence among ALHIV on second-line ART during their daily interactions.

2. Theoretical Framework

Adherence to ART is a complex phenomenon influenced by the interplay between the context in which a patient is expected to adhere to the prescribed medication and the relationships with family, friends, community and other social elements that influence his/her life (Berben, et al., 2012). The study adopted the Social Ecological Perspective (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). The premise underpinning this framework is that whereas individuals are responsible for instituting and maintaining lifestyle changes necessary to reduce risk and improve health, individual behavior is influenced by factors at different levels and thus gives greater attention to the social, institutional and cultural contexts of people-environment relations (Edler, et al., 2007). Furthermore, at this stage, adolescents are interested in seeking answers to questions through communication with those within their environment, including family, friends, social media, school and healthcare providers. It is against this background that the researcher sought to explore CTCs on adherence to ART among ALHIV in a rural context.

2.1. Research Method

This study used ethnographic research design to collect both quantitative and qualitative data for a period of one year (November 2017 to December 2018) in Gem sub-county of Siaya County. The research period was sub-divided into four phases. Each research phase corresponded with public school holidays to allow the researcher access to respondents most of which were in various institutions of learning. The study was carried out in 6 PSCs sampled from 29 public PSCs within the sub-county which is predominantly rural inhabited by the Luo ethnic group. A sample size of 37 (19 male and 18 female aged 15-19 years) ALHIV on second-line ART was arrived at using multi-stage sampling method coupled with purposive sampling to obtain 13 key informants and both biological and social caregivers as respondents for the study. The study used in-depth interviews (IDIs) and focus group discussions (FGDs) to collect qualitative data from the study participants.

2.2. Data Collection, Preparation and Analysis

After gaining rapport, the study identified 10 (7 male and 3 female) ALHIV on second-line ART which the researcher subsequently engaged in IDIs. The researcher visited each ALHIV four times in the course of this period with each session lasting two hours. The IDIs were audio recorded. Informal interviews were also utilized as they assisted the researcher to situate conversations regarding the research objectives within the lived experiences of the respondents. Our study also administered semi-structured questionnaires to 37 (19 male and 18 female) ALHIV on second-line ART. The study also conducted 3 FGDs with 8 male and 8 female ALHIV on second-line ART as well as 8 caregivers of ALHIV on second-line ART. To facilitate the FGDs, two key informants arranged room within one PSC that acted as the venue. The researcher moderated the discussions with a research assistant taking fair notes. The discussions were also audio recorded with each FGD lasting two hours. The researcher listened to and transcribed the audio tapes and read the transcripts over and over again to familiarize herself with the data collected. Content analysis was employed to elicit patterns and themes that the researcher used to establish explanations and deductions.

2.3. Ethical Considerations

The study sort a research permit from Maseno University Ethics and Review Committee, and permission from Centre for Health Solutions (CHS) as it has a supervisory role over all the public PSCs in Gem Sub-County. The study also sort 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 on second-line ART and their caregivers. The study sort written informed consent from caregivers who accompanied the ALHIV on second-line ART to the PSC and assent from ALHIV on second-line ART.

3. Results and Discussion

3.1. CTCs on Adherence-related Activities and its Influence on Adherence to ART

In this study, adherence levels, good/poor, were based on self-reports from ALHIV on second-line ART, who were study participants. These were also validated by adherence counselor, in every sampled PSC, using viral load (VL) test reports of ALHIV on second-line ART done at a six-month interval. Good adherence in this study referred to ALHIV who had suppressed VL of less than 400 copies with the lowest reported being 37 copies whereas poor adherence referred to unsuppressed VL of more than 1000 copies with the highest reported being 112,000 copies.

ART Adherence	Good Adherence		Poor Adherence		Total
	NO	YES	NO	YES	
Presence of CTCs					
Female		12	4	2	18
Male	1	9	5	4	19
Total	1	21	9	6	37

Table 1: Relationship between ART Adherence and Presence of CTCs

As indicated in Table 1, among 37 ALHIV on second-line ART, 27 reported having some form of discussion with their caregivers, while 10 said they had no experience of such talks at all. Among ALHIV (27) who reported having engaged in some form of CTC, 21 of them exhibited good ART adherence while 6 had poor adherence despite reporting CTCs. The 10 ALHIV who reported a lack of CTCs also experienced poor adherence as well. This pointed to the importance of CTCs in promoting adherence to ART among ALHIV. In addition, it was important to establish whether discussions on knowledge of adherence-related activities formed part of CTCs among those ALHIV who reported discussions with their caregivers. Our study sort to explore whether ALHIV on second-line ART could identify and/or name their ARVs because it has been reported previously that ALHIV who understand what antiretroviral drugs they are on, how the drugs work and common side effects are in a better position to take care of their health (UNICEF, 2016). Similarly, according to SEP (Gombachika, et al., 2012), the micro system encompasses characteristics that influence behavior, such as, knowledge, attitudes, skills and beliefs. Our study thus, sort to establish whether ALHIV on second-line ART knew and could identify either by name or appearance, the specific ARVs they were taking and whether they discussed such knowledge in CTCs in instances where they occurred.

Gender of ALHIV	Female		Male		Total
	NO	YES	NO	YES	
Knowledge of ARVs					
Good Adherence		12		9	21
15		4		4	8
16		1		1	2
17		3		4	7
18		1			1
19		3			3
Poor Adherence	5	1	5	5	16
15	5	1	4	1	11
16			1		1
18				2	2
19				2	2
Total	5	13	5	14	37

Table 2: Relationship between Knowledge of ARVs and Adherence to ART

Table 2 shows that 21 ALHIV on second-line ART who had basic knowledge of the ARVs they were taking, that is, they were able to identify their ARVs by appearance, had good adherence as opposed to those who did not know their ARVs and thus exhibited poor adherence. Similarly, those 21 ALHIV had also previously reported engaging in CTCs with their caregivers. In addition, older ages of 17, 18 and 19 years were more knowledgeable with regards to the ARVs they were taking than younger ages of 15 and 16 years. Among ALHIV on second-line ART aged 17-19 years who knew their ARVs, majority (9 out of 11) could identify them from a shelf consisting of other ARVs they were not taking. However, only 3 (2 male and 1 female) ALHIV on second-line ART knew their ARVs by name. However, despite having knowledge of the ARVs, 4 male ALHIV (2 18 year olds and 2 19 year olds) still had poor adherence. These 4 male ALHIV were part of the 6 ALHIV that exhibited poor adherence despite reporting presence of CTCs. Other socio-cultural factors such as home background, orphanhood status and personal resilience (discussed in a separate paper) could be said to influence adherence levels among ALHIV.

Inability to identify and/or name one's ARVs among ALHIV on second-line ART aged 15 and 16 was a cause of concern as they constituted 60.5% of the study sample and out of 16 that reported poor adherence, they accounted for 12. Majority of this age group (44.7%) were in primary schools and probably this contributed to their inability to identify and name their ARVs. They also lacked CTCs as caregivers thought they were still young to be engaged in 'adult talk' (discussions on issues of HIV). Three ALHIV aged 15 years had only partial information as to why they were taking drugs every day. This finding is consistent with those of studies in other contexts which have reported that many ALHIV on ART in the Asian Pacific lacked critical knowledge about ARVs and ART regimens and did not know the name of their treatment regimen (UNICEF, 2016; Yang Yu, et al., 2018). Knowledge of one's ARVs was important because, as the study found out, in instances where ALHIV on second-line ART moved to other PSCs without official transfer letters or in instances where a health care provider mistakably dispensed wrong ARVs, then ALHIV on second-line ART would be in a position to remedy the situation before harm occurred. A female caregiver who engaged in CTC reported during an IDI that knowing the ARVs her son was taking saved the situation. She narrated that:

There was a time I travelled and he went for pill refill while am away. After a short period of time, he started complaining of persistent headaches that were not stopping even after I gave him panadol. You know we have been taught

that when something like this happens, we check if the drugs are being taken as the doctor said. So I told him to bring them so that I can be giving him myself. But when he brought, I immediately saw that one bottle was smaller than the other one. Usually his bottles are of the same size. Am not able to read the names of the drugs, they are very difficult but I knew that small bottle was not his so we went to the doctor who was sorry for the mistake but was also very happy that we saw the mistake before it took long (IDI with a female caregiver).

Such instances could be rare, but whenever they occurred, knowledge of one's ARVs can help correct the mistake before a lot of damage happens to one's health. During caregiver interviews and an FGD with caregivers, our study observed that caregivers on ART were able to identify their own ARVs and those of ALHIV on second-line ART under their care as compared to their counterparts who were not on ART. Those caregivers on ART were also more open in their CTCs with ALHIV under their care. One female caregiver of a male ALHIV on second-line ART who reported engaging in CTC and was also a PLHIV during an IDI reiterated that:

I know them, we started early, and he was 8 years old. It is like my food; it is in my mind, so I know them. I also know mine and I have told him why he is taking ARVs so he is comfortable (IDI with a female caregiver).

Our study concurs with that done by Katko, et al., (2002); Wrubel, et al., (2011) and Arika (2011) which reported that parents of adherent children were able to identify the drugs their children were taking and also had higher perceptions of their ability to administer the prescribed ARV dose.

Coupled with ability to either identify and/or name one's ARVs, it was necessary to establish whether ALHIV on second-line ART knew how (referring to biological rationale) ARVs work in their bodies as an adage goes 'knowledge is power'. Knowledge of how ARVs work was important as it helped to emphasize why the drugs were to be taken as prescribed without missed doses or delay in timing, reasons that influenced persistent poor adherence exhibited by ALHIV on second-line ART. Study findings showed that out of 21 ALHIV who reported engaging in CTCs and exhibited good ART adherence, 18 knew what the ARVs were doing in the body but not how the ARVs work. The ALHIV on second-line ART said that ARVs 'duoko rateke mag kute chien', (ARVs reduces VL), others said ARVs 'mero kute' (ARVs makes the virus sleep). In essence ALHIV on second-line ART were aware that the main role of ARVs in the body was to reduce ones' HIV VL, but had no knowledge of how the ARVs accomplished this role. This finding is in line with a study conducted in South Africa by Hornschuh, et al., (2017) which observed that even though participants had difficulties in explaining the biological rationale of why ARVs had to be taken as prescribed, they were aware of what ARVs did in the body, mainly reducing VL. The remaining 19 ALHIV could not relate ARVs and reduced VL despite 3 having good adherence and 9 reporting having engaged in CTCs. They were simply taking drugs as instructed. Again age and level of education could be a cause of lack of this knowledge. This shows that other socio-cultural factors such as family support, one's attitude, skill and beliefs and how these interacted with the social context of the ALHIV as espoused by SEP could also influence adherence to ART. Furthermore, engaging in CTCs was not enough assurance that ALHIV will adhere to ART. Consequently, whereas individuals are responsible for instituting and maintaining lifestyle changes necessary to reduce risk and improve health, individual behavior is influenced by factors at different levels and thus gives greater attention to the social, institutional and cultural contexts of people-environment relations (Edler, et al., 2007).

3.2. Content of CTCs and ART Adherence

ALHIV on second-line ART reported various topics that were discussed across the board with varying degrees. Conversations on housework were reported by all 27 ALHIV who reported having engaged in CTCs with only 21 exhibiting good adherence. In addition, 23 out of 27 also reported discussions on academics/school work. Discussions on academics majored on advising ALHIV to work hard in school and build a better future for the family.

My mother always advises me to work hard at school and control my emotions that enjoyment will come later. She tells me that only education will give me a good future and enjoyment will only spoil my life. (IDI with male ALHIV)

My father works in Nairobi but whenever he came home, he was concerned with how I had performed at school and advised me to work hard and build our home, and also how the farms had been worked on. (IDI with female ALHIV)

According to our research findings, caregivers found it easier to discuss matters related to school work and other general topics such as farm work and housework. These general issues our study observed, had little emotional energy involved and did not reflect on one's private life, either of the ALHIV on second-line ART or that of the caregiver. This made the CTC 'safer' and thus sidelined ART adherence knowledge that could lead to discussions on private and personal issues such as sexual relationships, which would elicit discomfort or even embarrassment especially on the part of the caregiver. Caregivers, in this instance could be said were 'hiding' behind general topics to avoid discomfort and may be also due to generation gap as Obwaka, et al., (2004) also noted that in other instances, parents/caregivers may also be influenced by the generation gap with associated feelings of embarrassment while discussing sexuality issues. This has negated the knowledge flow that was envisaged would trickle down to ALHIV on ART (Birungi, et al., 2011; UNICEF, 2016; Yang Yu, et al., 2018).

The study found out that even among 19 ALHIV on second-line ART whose primary caregivers were grandmothers, the discussion still concentrated on academics and school work which was seen as a source of hope for a better future as exemplified by this extract:

I fear my father because he is always quite but with my grandmother (is a maternal orphan), all she says are do housework well, work hard at school and one day build me a good house. (Female ALHIV: an FGD discussant).

Similarly, the study also realized that contrary to traditional expectations of grandparents as agents of adolescent sexual learning, some ALHIV reported that their grandmothers did not discuss with them how to deal with relationships but to avoid such;

My grandmother keeps telling me to just stay the way I am and avoid girlfriends especially because of my status. If I ask her what is wrong with having girlfriends, she tells me that girls will make me fail in school (IDI with male ALHIV).

I talk with my grandparents. We just compare what was there traditionally and what is now. My grandfather tells me stories of how he used to buy and sell cows with little money those days. Today life is very hard and one needs a lot of money even to feed well (Male ALHIV: an FGD discussant).

This was contrary to cultural expectations of grandmothers. Studies have reported that among the Luo community, grandmothers were key players in adolescent sexual learning (Cohen and Atieno-Odhiambo, 1989). One reason for this scenario could be age, implying that women nowadays become grandmothers while they were still in their reproductive age thus contributing to the uneasiness witnessed whenever sexuality issues were mentioned by ALHIV. It could also be stated that grandparents had assumed the roles of parents (with the death of their children as a result of HIV and AIDS) with full responsibilities typical of parental roles involving authority and provision for the basic needs of the family. This according to Alber (2004) makes it difficult for grandparents to mix with the expected grandparental behaviour involving joking, warmth and proximity to their grandchildren which led to an easier flow in discussions concerning adolescent sexuality. Furthermore, because grandmothers have now assumed parenting roles, coupled with their relatively younger age, the taboo nature of sexuality discussions between adults, particularly parents and their children in SSA has impacted on the traditional expectations of grandmothers (Mbugua, 2007; Paruk, et al., 2005; Amuyunzu-Nyamongo, et al., 2005).

Sexuality is one of the main domains that encourage adolescents to create a sphere of individual autonomy with experiences therein influenced by the environment in which they live. Furthermore, at this stage, adolescents are interested in seeking answers to questions regarding sexuality matters, through communication with those within their environment, including family, friends, social media, school and healthcare providers. Research has shown that most adolescents become sexually active by age 15 (Jose, et al., 2012). Similarly, in this context, just as in SSA, ALHIV may have acquired HIV through sex. The study engaged 10 (7 male; 3 female) ALHIV on second-line ART as respondents for IDI. Only 2 (1 male; 1 female) reported not having either boy/girlfriend. The remaining 8 had boy/girlfriends that they actually referred to as 'jaherana' 'my lover' out of which 2 female and 3 male reported being sexually active. In fact, both the two female ALHIV on second-line ART and one male ALHIV on second-line ART were behaviourally-infected adolescents (BIAs). In addition, during FGDs both for male and female ALHIV on second-line ART, all the discussants, both male and female, reported having boy/girlfriends. However, out of 8 male discussants, 6 were sexually active while 2 were not and out of 8 female discussants, 7 reported being sexually active and 1 said they were yet to initiate sexual activity with their lovers. One male ALHIV on second-line ART who did not have a girlfriend reported during an IDI that I am still controlling it, my feelings. Our study thus thought it was needful to explore whether sexuality issues formed part and parcel of CTCs among our respondents who reported having engaged in CTCs.

Out of 10 ALHIV who were respondents of IDIs, only 4 reported having had discussions on sexuality related topics, such as condom use during CTCs. Similarly, during an FGD with caregivers, 5 (4 female and 1 male) caregivers reported having engaged in sexuality related topics during CTCs with ALHIV on second-line ART under their care. Discussions on sex related issues hinged on using the adolescent's ART status as a point of reference to what sexual activity can do to someone if they are not watchful. For instance, a male caregiver talked to his daughter in this manner:

I tell her that this disease that has made her to be taking drugs everyday does not want her to be with someone most of the time as this increases it as you may encounter someone whose strain is different from yours. (IDI with male caregiver).

Other caregivers also used past occurrences/situations to initiate discussion between them and ALHIV under their care. For instance, one female ALHIV narrated that:

Whenever my parents remember my sister's case (who got pregnant while in secondary school (form three), but has since given birth and returned to finish school), they tell me men lie to people so I should be very careful not to fall in the same pit that my sister fell into (IDI with female ALHIV).

When asked whether discussions about ALHIV's sexual activities, for example condom use formed part of CTCs, one caregiver said that:

I am free with my son; I have told him condoms are available at the PSC even though they are not openly displayed. I encourage him to just feel free with the doctor and ask him for some whenever he goes to the hospital (female caregiver: an FGD discussant).

This concurs with Wamoyi, et al., (2010) who reported that discussions between parents and their teens typically consisted of warnings, threats and physical discipline and was triggered by seeing or hearing something a parent perceived as a negative experience, for example, death attributable to HIV and an unmarried girl's pregnancy. Our study also observed a sense of an acceptance of sexual activity among ALHIV on second-line ART by their caregivers. This was contrary to societal expectations as pre-marital sex was traditionally abhorred among the Luo with sexual purity and virginity until marriage being rewarded with a high moral standing in the community not only to the girl but also to the mother (Suda, 2000; Kilbride and Kilbride, 1990). In the CTCs, sexuality topics were mostly related to abstinence, condom use, and pregnancy but were not expressly connected to ART adherence whatsoever. For instance, there were no reports of discussions entailing the connection between unprotected sex and HIV re-infection as well as ART status disclosure to sexual partner. Similarly, none of the ALHIV and the caregivers reported discussing how onset of sexual activity may hinder adherence to medication through missed doses and delayed timings as a result of ALHIV trying to control the situation so as not to expose their ART status. On the contrary our study observed a carefree attitude towards sexuality without a corresponding attention on how it would influence ART adherence. This negates the notion of treatment as

prevention championed by various stakeholders in HIV care and management (WHO, 2016) as it would not accrue maximum benefits if ALHIV were not adherent. Consequently, as espoused earlier by SEP, adherence was no longer an individual affair but a relational one and therefore, caregivers were still under the obligation to ensure that they influenced decisions made by ALHIV on when, how and why to adhere through CTCs so as to ensure their prolonged stay on second-line ART regimen.

On the contrary, 10 ALHIV reported not having any form of CTC with their caregivers. The main reasons being that parents thought ALHIV were still young and therefore could not be involved in 'adult talk'. Other ALHIV reported that their parents were too harsh and so were not able to hold any discussions especially related to sex and girlfriends. When asked during an FGD with male ALHIV if they were able to initiate CTCs, they denied. The following extract reiterates this assertion:

If you dare, the answer my mother will give you, will make you just go to cool off your heard at the market place. I cannot dare ask her anything of that nature; she can even beat me (FGD with male ALHIV). Other discussants immediately concurred.

Our study observed that between both caregivers and ALHIV on second-line ART, there was a high affinity to concentrate on matters sexuality whenever CTCs was mentioned. This probably could be due to adolescence as a developmental stage marked with onset of sexual aspirations as well as the education system that ensured most adolescents were in secondary schools that came with more room for independence and freedom as compared to primary schools. Consequently, on those instances where there were no CTCs, caregiver inability to initiate and hold discussions with ALHIV was influenced by inadequate knowledge concerning sexuality issues and not necessarily ART adherence related matters. Caregivers in this category felt that all they needed to talk about to ALHIV was sexuality related and because they did not know how to go about it, they opted to keep quite. Other caregivers were rather shy due to generation gap. For instance, when asked why there was no CTC:

It is like he is shy, laughs. No, he is too busy. You know he has another family. It is okay, I really do not mind, laughs. It is okay. I do not miss such talks because I am not there yet (IDI with male ALHIV).

We do not talk, but there is one time I sat him down and told him this drug is his life, if he plays with it, he will die. What will I tell him (she laughs as though is shy) may be you tell me how to go about it because as it is I do not know how to start talking to him about such like things. Maybe you can also talk to him a little to assist me, please (IDI with caregiver).

We do not talk about social issues, those ones he will be taught in school because that is what teachers are supposed to do but I tell him that if he does not take his drugs he will die. These drugs are his life (IDI with caregiver).

Most issues are fear and self-stigmatization. It is more helpful when caregiver is free with her status as it promotes acceptance and helps the ALHIV to fight stigma from peers. Some caregivers are very difficult and this also affects the ALHIV (adherence counselor: key informant interview).

The study also found out that the decision to engage in CTC and whatever to discuss was also dependent on the ART status of the caregiver and how they perceived it. Caregivers who had disclosed their ART status to other people outside their nuclear families were more open to discuss with ALHIV under their care matters related to ART adherence, and most often used themselves as examples to encourage ALHIV to adhere to medication. On the contrary, caregivers who had hid their ART status were uncomfortable talking about ART as it reflected on themselves, especially in instances where ALHIV were PIAs. This finding may not fully agree with the observation made by Nostlinger, et al., (2016) stating that HIV positive parents avoid discussing HIV-related matters with their ALHIV due to feelings of guilt and shame. This is because it did not consider ART disclosure and its resultant effects on caregiver openness to discuss ART issues with ALHIV under their care.

Among caregivers who were not on ART, CTCs were highly influenced by caregiver knowledge of sexuality issues. In addition, the researcher observed that social caregivers such as aunts and step mothers were more willing to discuss sexuality matters with ALHIV. Furthermore, social caregivers were more open and talked in loud tones during field visits as compared to HIV negative biological caregivers who felt uneasy discussing ART status of their BIAs and talked in whispers and low tones. This openness evident among social caregivers could be attributed to a lack of personal responsibility in relation to how the ALHIV acquired HIV infection and thus any discussion on the same was not reflective of their own private lives. Caregivers of BIAs uneasiness could be acting as a shield to protect their ALHIV from community stigma as well as a feeling of guilt probably for not bringing up a sexually moral child. Our study, however, noted that whenever a caregiver reported discussing ART issues with ALHIV on ART, it most often boarded on a carefree "if you do not take your drugs you will die" kind of an attitude.

3.3. Other Issues That Did Not Form Part of CTCs though Were Desired and Adherence to ART

It was reported by ALHIV that caregiver attitudes that promoted 'unconcerned/carefree talk' hindered effective CTCs, especially on matters that were of interest to ALHIV. Consequently, some ALHIV still relied on their peers as their points of reference as they claimed that caregivers were too busy:

They (caregivers) tell you if you do not take your drugs, it's up to you; if you ask on some issue, you are told that such things have already put you on drugs but you still cannot see, you will follow your mother and stop disturbing people around here (female ALHIV: FGD discussant).

Such comments hindered those ALHIV on second-line ART from approaching their caregivers with emotional issues affecting them thus preferred to talk to their friends. Other issues of interest to ALHIV to form part of CTCs included contraception, especially with regards to whether they would still be able to have children when they eventually stopped

using them and the possible side effects. Another concern was related to school work and ALHIV desired that caregivers should not generally talk about working hard in school:

Like right now I will be going to form three and am supposed to choose some subjects and drop others. I do not know how to go about it so that I do what will make me get into a good course in college (IDI with female ALHIV).

Another concern for ALHIV was that caregivers would learn to explain their reasons for denying certain types of activities and not just insist on not granting permission. As a matter of fact, some ALHIV reiterated that as much as caregivers prevented them from going to social gatherings, they always found ways of circumventing such rules, for instance:

My grandmother denied me from going to a youth meeting organized by my local church and yet did not explain why. She thinks that am still young and do not make love, yet my boyfriend come to me at night where I sleep in her kitchen (female ALHIV: FGD discussant).

Male ALHIV, during an FGD, on the other hand, desired caregivers to talk about the challenges they had passed through in life. They also wanted caregivers to be open and give straight forward answers. For instance:

Whenever I inquire about an issue from my mother, she brings a discussion that goes round and round, that may eventually solve my problem but do not answer me straight. This at times is very frustrating and I do not like it at all (Male ALHIV: FGD discussant).

In addition, other male ALHIV during an FGD also desired that their teachers, especially those in day schools, would acknowledge their presence and put in words of encouragement to motivate them to continue taking their drugs and also sensitize other students on ART issues so that they could be free to take their drugs in school. This desire was also reported by a social worker who acted as the caregiver of ALHIV residing in one orphanage. She said that:

As much as we talk to our ALHIV and sensitizing them on matters to do with ART, who is talking to those in schools who are not on ART to make them accommodative and sensitive to the plight of ALHIV on ART? (IDI with caregiver) The study also explored caregivers' views on the desires expressed by ALHIV in relation to CTCs. Most caregivers (6 out of 8 in an FGD) concurred that it was lack of knowledge on some issues, such as the side effects of contraception that hindered them from holding discussions on the same as they feared misleading their ALHIV. Other caregivers (2 out of 8 in an FGD) however, were of the opinion that parents were supposed to be strict and to discipline their children and it was difficult to do so if one was not harsh. The following excerpt reiterates:

There is a stage where one must assume some things from adolescents. You do not have to respond to everything you hear from them. There has to be rules in the home and this is paramount in order to maintain discipline. There are times I have to be strict so as not to be overruled by these children who grow so fast nowadays (Female caregiver: FGD discussant).

She thus reiterated that a caregiver would at all times be either soft, slippery or hard and it was up to the ALHIV on second-line ART to know when to approach them and with what desire or problem. The study also met 4 caregivers of ALHIV, who were respondents of IDIs, who desired to talk about certain issues but they did not have adequate information related to those particular issues. This as it was found, hindered the caregivers from actively engaging in CTCs. For instance, one female caregiver during an in-depth interview inquired whether it was right to allow a male ALHIV to go for circumcision. Another wanted more information relating to methods of contraception, especially on their side effects claiming that prevention was better than cure and that she did not want her daughter to get pregnant before finishing school. This caregiver thus claimed she needed this kind of information to be able to advise her female ALHIV accordingly. It was also evident from the study findings that some caregivers were struggling with the supposed HIV status of the future spouse of their ALHIV and wanted to know more about what was the best option under such circumstances. This corroborates with a study conducted in Burkina Faso, Ghana, Malawi and Uganda which reported that while the proportion of adolescents reporting having discussed sex-related matters was low (8-38%), the proportion reporting communication about contraceptives was even lower with no more than 10% (Biddlecom, et al 2009).

On the contrary, our study encountered 2 caregivers who were apathetic to CTCs claiming that things have changed from traditional times and that ALHIV were hot headed and did not listen:

Even when you talk, they do not listen, they do not care. Traditionally, there used to be teachings for youths on how to behave whenever they visited their lovers but nowadays there are none and it makes it difficult to direct their steps. Today sex underlies every encounter the youth make as compared to our days. In fact today the length of courtship is shorter than in traditional times (FGD with caregivers).

4. Conclusion

This study established that there was sufficient ART adherence knowledge among both ALHIV on second-line ART and their caregivers. Second, our study witnessed a disconnect between knowledge and behaviour among ALHIV on second-line ART which saw poor adherence being reported even among those with sufficient ART adherence knowledge. In addition, there were sufficient CTCs going on among ALHIV on second-line ART and their caregivers. There were notable efforts during CTCs in ensuring that ALHIV were always reminded of their ART status in a bid to ensure adherence to ART. The study however, noted a concern, in that, as much as sufficient CTCs were reported, with varying issues of discussion, specific ART adherence knowledge was not evident. For instance, matters relating to ART status disclosure to sexual partner, HIV re-infection and HIV drug resistance that have been shown to influence suboptimal adherence among ALHIV were not expressly evident in CTCs. Consequently, the expectation from some interventions that knowledge would trickle down from PLHIV who were caregivers/parents of ALHIV to their teens could not be denied or accepted due to the fact that such intervention strategies did not specify what sort of knowledge was to be passed down to ALHIV. This could

be explained with the fact that despite reporting presence of CTCs, some ALHIV still had poor adherence. Therefore, in as much as our study would suggest a shift from targeting people living with HIV to more focused interventions for ALHIV, it recognizes that knowledge alone was not sufficient to ensure adherence to ART. There was need to explore other socio-cultural and demographic factors such as social support, orphanhood status and individual resilience in promoting ART adherence among ALHIV on second-line ART. This is in a bid to ensure ALHIV stay on the second-line ART regimen for as long as possible as third-line ART regimen was not readily available and affordable in this context.

5. Study Limitations

This was an ethnographic study that endeavored to understand in-depth matters related to ART adherence among ALHIV on second-line ART and thus had a small sample size of 37. Its findings may thus not be generalizable to bigger populations. This study also only targeted ALHIV on second-line ART because they already had reduced future therapeutic options despite their young age implying therefore that the scenario on ART adherence knowledge as components of CTCs could be different among ALHIV on other ART lines/regimens.

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