Influence of Caregiver and Peer Support in Adherence to Antiretroviral Therapy amongst HIV Positive Adolescents Attending Murang'a County Hospital.

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Abstract

Introduction: The number of youth and adolescent infected with the Human Immunodeficiency Virus is increasing globally. In 2019 alone, an estimated 460,000 young persons between 10 to 24 years globally were reported to be newly infected with HIV. Antiretroviral therapy is an effective approach to management for adolescents living with HIV. Maximum suppression of the virus improves the quality of life and health outcome. In May 2020, Murang'a County reported viral load suppression in ages between 10-14 years of 87.2% while 15-19 years was 86.7%. However, viral suppression requires optimal drug adherence and behavior change that is influenced by approaches such as care givers and peer support. Optimum caregiver and peer support in sub-Saharan Africa is thought to hinder adolescent adherence to ART. The study aimed at assessing the influence of caregiver and peer support in adherence to antiretroviral therapy amongst HIV positive adolescents attending Murang'a county hospital. **Methodology**: A cross sectional study was carried out at Murang'a County Comprehensive Care Center among 93 purposively sampled adolescents and selected key informants. Data was collected using semi-structured questioners and key informant guides. Quantitative data was analyzed using SPSS; both descriptive and inferential statistical techniques were used. Qualitative data was manipulated manually through thematic analysis. **Results**: From the study, females (56%) and (44%) males took ART as prescribed. Many (65.7%) had secondary education whilst 19% had reached college/university level. Majority were Christians (92.4%) while Muslims were (5.7%). Mothers (37.6 %), fathers (9.7%), and both parents for (29%) took care of them. Respondents who did not attend support groups at Murang'a CCC cited distance (54%), being busy (15%) and bad timing (15%) as challenges. However, adolescents visiting Murang'a CCC received parent and school support. They ensured that their children took medication and visited clinic as required. Frequency of support group attendance was found to be statistically significant to adherence (p=0.002). **Conclusion**: Reinforcement of care giver support frameworks and promotion of peer support among ALWHIV is fundamental in fostering ART adherence among adolescents in Murang'a County. Availability of mHealth platforms such as WhatsApp is an opportunity to scaling up peer support among adolescents who experience challenges with distance and competing priorities.

Keywords: ***Adherence, Accessibility, Drugs, Family, Influence, Medication, Teens, Support.***

Introduction

Morbidity and mortality resulting from HIV/AIDS is an ongoing global concern more so in the low income countries. It is estimated that more than 37.9 million were living with the virus in 2019, while 770,000 had died (World Health Organization [WHO], 2018). In 2019, 25.4 million people living with HIV were estimated to be accessing antiretroviral therapy. Of concern is that nearly 7.1 million people globally, were not aware that they had been infected with HIV (United Nations Programme on HIV/AIDS [UNAIDS], 2020). Notably, the youth and adolescent are among a section of the populace recording an increasing number of persons living with HIV globally. An estimated 460,000 [260,000-680,000] persons between 10 to 24 years globally were reported to be newly infected with HIV in the year 2019 only. Out of this, approximately 170,000 [53,000-340,000] were adolescents aged 10-19 years. Moreover, in the East and Southern parts of Africa, 27% female and 16% of male adolescents in 2020 were reported to have been tested in the preceding 12 months. According to the United Nations Children's Fund [UNICEF] , the Western and Central Africa together with South Asia have the least proportions of testing and if the trend remains, an estimated annual 183,000 incidences will be reported among adolescents in 2030 (UNICEF, 2020).

In 2018, the Kenya Population-based HIV Impact Assessment [KENPHIA] reported prevalence of HIV among adults to be 4.9%, meaning that 1.3 million adult Kenyans were living with the virus. The disease burden in women (6.6 %) was noted to be two times more than that of males (3.1%). Among the adolescents (10-19 years) the prevalence was reported to be 0.9% (NASCOP, 2020). From the same report, Murang'a had a prevalence of 3%, this estimate was lower than that of 2018 where the county had 4.2% from the National Aids Control Council [NASCOP] report. The county had been highlighted as having the highest HIV prevalence alongside Kisii, Transzoia, Nyamira, Makueni counties (NASCOP, 2018).

The Joint United Nations Programme on HIV/AIDS [UNAIDS] envisions to end the HIV pandemic. One of the approaches was through the 90:90:90 target which was to be achieved by the year 2020. The intention was that by the year 2020, 90% of all people living with HIV (PLWHA) will have known their HIV status, 90% will have been enrolled to care and sustainably receiving ART and 90% on ART will have achieved viral load suppression (UNAIDS, 2014). Globally, 81% of PLWHA knew their HIV status. Of those who knew their status, 82% were accessing treatment. And among people accessing treatment, 88% were virally suppressed in 2019 (UNAIDS, 2020). In Kenya, results from KEPHIA reported viral suppression prevalence of 71.6% populace of 15- 64 years while adolescent 61.6%. Adolescent rates were lower compared to the youths and adults.

Achievement of the 90:90:90 targets in Kenya require concerted effort between the counties and the national government. Antiretroviral therapy has been demonstrated to be the best effective management for PLWHA. It however relies on the level of patient drug adherence and behavior. The higher the adherence levels to drugs, the high the viral load suppression (Yu *et al*., 2018). Additionally, adherence is dependent on the entire process from choosing, medication initiation and maintenance and sustainability in care. Non-adherence on the other hand is the discontinuity

or termination of part or all of medication, this includes; missed dose, under dosing, overdosing, and drug breaks. The adherence is taken seriously as it is essential in maximizing patient's response to therapy that subsequently leads to viral suppression. Non adherence can lead to serious problems such as medication failure, increase in viral load, and eventually growth of medication-resistant HIV genotype (Laisaar *et al*., 2013). Adherence is assessed using either drug event monitoring system, pill counting, prescription refill, and individual adherence reports system (Jima & Tatiparthi, 2018)

Like many other drugs taken life long, achievement of desired levels of adherence to ART is remains a challenge globally. Interestingly, (Sangeda *et al.*, 2018) argued that adherence to ART in sub-Saharan Africa is higher or maintained at the same level as compared to industrialized nations. In low income countries, self-reported adherence level ranged between 78% -96%, while in the developed world, it ranged from 44% to 66%. Even with this high adherence levels, hindrances to adherence are observed to be country specific. In Kenya challenges cited include; pill burden, unawareness ART side-effects, disclosure, stigma among others (Ministry of Health, 2016) and social support (Kioko & Pertet, 2017). Moreover, life as an adolescent or youth, depression, substance abuse, poverty and lack of food are also cited as non-adherence factors (Micheni *et al*., 2017)

Adolescent adherence to ART is so much dependent on individual and health provider factors (Iacob *et al.*, 2017). According to NASCOP, (2020), 79% of adults aged between 15-64 years who tested HIV positive in KEPHIA 79.5% had prior knowledge of their status this was based on self-reporting and laboratory diagnosis. Negative perception either from the patients or health workers can also impede quality of care and access to care. Health worker support and patient forgetfulness affects adherence among HIV positive patients (Ankrah et al., 2016) . Patient trust and confidence are dependent on good patient-health worker relationship, subsequently influences patient treatment uptake, access to care and compliance to adherence. It is important to note that adherence level varies depending on the set of population group. The adolescents are recognized to be a very important group as they contribute to over 40% of the HIV incidences. Moreover, the adolescent are essential in subsequent evolution of HIV. They are an active populace and are a concern in coital spread (Croome *et al*., 2017).

Social support is the assistance that an individual gets from persons within his or her social linkages. Family members and friends can provide support to ALWH in diverse ways that enables the adolescents to adhere to their ARV treatment. Literature has shown that family members provide support by assuming the responsibility of reminding them about medication, clinic visits and also accompanying them to the hospital. Family members have been found to be very important in monetary, clothing and food support. However, notwithstanding the special developmental requirements of teenagers, very few research studies have focused on family structures among HIV-infected adolescents in Kenya. Moreover, in Sub Saharan Africa (SSA), studies done have not clearly investigated the correlation between caregiver support and adherence. Care giver support is essential in HIV management and adherence to treatment guidelines among ALWH, (Nabunya *et al.*, 2020).

Projections of ART adherence among adolescents living with HIV (ALHIV) in developing nations differ significantly. Furthermore, deficiencies in the rates of non-adherence among ALHIV in Sub Saharan Africa still exist (Ridgeway *et al.*, 2018). According to Murang'a County HIV & AIDS strategic plan 2014/2015-2018/2019, the total number of adolescent in 2019 were estimated to be

19, 6738. Paucity of specific data on adolescents living with HIV still exists. Reported statistics indicate that 31,581 people were living with HIV in 2013 in Murang'a County, of which 28,700 were adults and 2,881 were children. Out of the 31,581 PLHIV, 7,177 adults and 656 children were accessing ART. By the year 2015, 32,781 individuals were living with HIV while 10,256 adults and 1,054 children on ART. According to the NASCOP ACT Dashboard, the total number of patients on ART captured in the District Health Information System in May 2020 were 15,814. Reported viral load suppression in ages between 10-14 years was 87.2% while 15-19 years was 86.7%. The information provided specifically on the adolescent group is scanty yet these subsets of persons are recognized as a special group with unique needs.

Adherence among adolescents living with HIV nationally is low compared to adults. Many studies have cited patient specific, caregiver, health facility-related and sociocultural dynamics as hindrances to adherence. The study therefore aimed at assessing the influence of caregivers and peer support in adherence to ART among HIV positive adolescents attending Murang'a hospital comprehensive care center. The output from the study would be valuable in informing policy nationally and at the county level. It may also promote strengthening of adherence to antiretroviral therapy (ART) regime approaches that would subsequently lead to improved quality of life and health outcome.

Materials and Methods

A descriptive cross-sectional study design was conducted at Murang'a County Hospital comprehensive care center (CCC). A sample size of 93 HIV positive adolescents (10 years-19 years) and staff working at the CCC selected purposively was used. Both qualitative and quantitative data collection techniques were used. Both qualitative and quantitative was collected using questionnaires, focused group discussions and key informant interviews respectively. Pretest was done to ensure reliability and validity of the data. All research assistants were trained prior to data collection.

Quantitative data was analysed using statistical package for the social sciences (SPSS) version 24, where both descriptive and inferential statistical techniques were used for analysis. Qualitative data was transcribed word to word and analysed through thematic content reduction. Data was then visualized using charts and tables.

Ethical clearance was sought from Kenya Methodist University ethical and research committee, and the National Commission for science, technology and innovation (NACOSTI). Hospital approval was given by Murang'a County department of health. All respondents were taken through informed consent and participation was voluntary.

Results and Discussion

The factors influencing adherence to ART are shown in table1. From the study, female (56%) respondents and 44% males took ART as prescribed. Many (65.7%) had secondary education while 19% had studied to college/university level. Majority were Christians (92.4%) while Muslims were (5.7%). The respondent reported that mothers (37.6 %), fathers (9.7%), and both parents for (29%) took care of them. In this study, mothers offered the greatest support to the adolescent as compared to the fathers. Adolescent adherence to ART is influenced by interaction between the caregivers or family, health care providers, society and culture and drugs medication

at different levels (Martelli *et al.*, 2019). The nuclear family from other studies has also been shown highly supportive (3.7 ± 0.6) followed by peer support groups (3.1 ± 0.8) (Kioko & Pertet, 2017).

Table 1: Factors influencing adherence to ART.

		Take drugs as prescribed		Total (n=93)	P Value
		No (n=2)	Yes (n=91)		
Sex	Male	0	41 (45.1)	41 (44.1)	0.199
	Female	2 (100.0)	50 (54.9)	52 (55.9)	
	Total	2 (2)	91 (98)	93	
Education level	None	0	2 (1.9)	2 (1.9)	0.034
	Primary level	0	12 (13.6)	12(13.3)	
	Secondary level	0	61 (67.0)	61 (65.7)	
	College/University	2 (100.0)	16 (17.5)	18 (19.0)	
	Total	2 (2)	91 (98)	93	
Care giver	Both parents	0	27(29.7)	27(29.0)	0.104
	Father	0	9 (9.9)	9 (9.7)	
	Mother	0	35 (38.5)	35 (37.6)	
	Adopted	0	2 (2.2)	2 (2.2)	
	Other	2(100.0)	18 (19.8)	20 (21.5)	
	Total	2 (2)	91 (98)	93	
Religion	None	0	2(1.9)	2(1.9)	0.919
	Christian	2(100.0)	84(92.2)	86(92.4)	
	Muslim	0	5(5.8)	5(5.7)	
	Total	2 (2)	91 (98)	93	
Attend any support groups	No	1 (14.3)	6(85.7)	7(7)	0.635
	Yes	9(10.2)	77(89.8)	86(93)	
	Total	10 (10.9)	83 (89.1)	93	
Frequency attend the meetings	Every time	2 (3.4)	57(96.6)	59 (63)	0.002
	Once in a while	8(25.0)	24(75.0)	32 (34)	
	Never	1(50.0)	1 (50.0)	2 (2)	
	Total	11 (11.8)	82(88.2)	93	
Reasons for not attending support groups	Busy	0	2 (100.0)	2 (15)	0.567
	Very far off	2 (28.6)	5 (71.4)	7 (54)	
	Bad timing	0	2 (100.0)	2(15)	
	Other	0	2 (100.0)	2(15)	
	Total	2(15.4)	11(84.6)	13	

According to Nabunya *et al*.,(2020), attainment of maximum ART adherence is reliant on the family unit which is viewed as an important unit that provides monetary and emotional support. In their study, family unity depicted ($p = 0.000$) and communication ($p = 0.026$) were significantly associated with adherence, this signified emotional support experienced by adolescents through frequent dialogue and care. Even though being an adolescent implies self-reliance to some extent, supportive structures and linkages family and caregiver are perceived as protective factors. More so for ALWH, family is a basic source of monetary, physical, and psycho-emotional support.

In Cuba, caregivers reported sufficient adherence in 17 of the 21 children. Non-adherence was associated with psychosocial factors such as extra obligation taken up by the caregiver while dealing with his or her own sickness, unmanaged mental symptoms in the caregiver, apparent challenges with family support and giving medication obligations to a minor without considering his/her psychological development (Castro *et al.*, 2015). Further, even though social support was demonstrated to be good by respondent in a study carried out Kioko & Pertet, (2017), 48.2% perceived it as inadequate. This places emphasis on families and care giver support as an important factor to optimal ALWH adherence to medication in Kenyan hospitals.

From the current study, health providers interviewed confirmed adolescents who has good social support were adherent to HIV management at the facility. This was a positive finding as it indicates that family and care givers played a big role in ensuring adherence. This may have also meant that barriers such as financial and psychological factors are tackled by the support structures therefore consistency in medication, adherence and improved health outcome. One of the counselors was quoted saying:

"Adolescents with good social support do follow their clinic and take their pills well" (Counsellor; KII)

In Uganda, lack of family support was reported to negatively influence adherence among adolescent (14-17 years) and youth aged 18 to 24 years. From the discussions, poverty was cited as a challenge since they were not able to buy food, this rendered them economically unviable, in addition to that, family support was not reliable because of persistent change of guardianship, and this was due to the fact that many had lost their biological parents to HIV (MacCarthy et al., 2018a). One respondent stated:

"…*but most times, we don't have people to help us, to guide us take our medicine, it's me."* (Youth boy age 18 and older.)

The importance of family support was expressed by the respondents. Being an orphan left them helpless. Majority of the youth were orphaned by HIV. One respondent explained the effect of being orphans in life:

"…when you don't have a mother [or] you don't have a dad, life is very, very difficult… Since I was born I have never seen my mum [or] my dad… in my heart [I know] that if mum was around, she would have [helped] me." (Youth boy age 18 and older).

The report recommended adolescent HIV programs and policies should factor in care giver support bearing in mind changes in guardianship among orphans. This obscures ART adherence especially due to biological and social changes faced by elder adolescents (MacCarthy et al., 2018b). Health facilities should strive to involve family in the day to day management of affected adolescents in the family. Such approaches would also eliminate stigma and discrimination from family and society at large.

As reported by MacCarthy *et al*., (2018b), school attendance caused lack of privacy among the adolescents which subsequently hindered ART adherence. However, in Murang'a County, the health workers reported that the hospital was working with schools through the matrons. The matrons would also be informed of students by parents on ART management and therefore would support the adolescent hospital visits and taking medication in timely. One of the health workers stated:

"*We are doing now; we make sure we send the parent or social worker or peer educator to go talk to the matron and tell them about the status of that pupil or student…we ensure that the parent talks to the matron so that the student can continue taking the drugs or go to the clinic because of if the matron knows even know coming to the clinic or borrowing permission will be easier and they will improve their adherence and retention."* (Counsellor, KII)

Adolescents visiting Murang'a CCC were reported by health workers to receive parent support. They ensured that their children took medication and visited clinic as required. Further, adolescents who persistently missed clinic visits, follow up was done by health workers to their homes. One of the Counselors stated:

"*They have treatment supporters; the parents, they support them a lot they come with them to the clinic; they learn together that's another thing that keeps them coming to the clinic… We are also doing home visits to make find out if there is a problem or if there are challenges, they are facing at home to know who the treatment supporter is wherever we can help.*" (Counsellor, KII)

Support groups were attended by 93%, the meetings were attended every time by 63% and once in a while by 34%. Although support groups did not show any statistical significance in adherence, the frequency of the meetings showed otherwise (p=0.002). Support groups or participation in clubs however among ALWH in other settings have been shown to influence adherence. Integration of support groups in HIV management is an effective approach for improving patient literacy as well as a medium of tackling psychosocial needs (Bateganya et al., 2015).

Use of support groups in South Africa is seen as practical measure of scaling up and sustaining adherence of patients living with HIV. Moreover, use of mHealth in psychosocial support groups

to improve adherence among HIV positive adolescents was tested, it was proved to be effective in scaling up adherence among adolescents in South Africa. The peer to peer support group was thought to be an enabling environment for behavior change too. The participants would remind each other to take medication, advised each other on how to handle pill side effects at the same time finding solutions among themselves of how to fit into the daily activities of life. The results showed an increase (6.8%) in social support, decrease in stigma and also increased rates of adherence self-reporting (de Jager *et al.*, 2018).

The importance of peer networks was illustrated by one of the respondents who explained how one of his HIV-positive friends motivated him to continue taking his pill even as he fought to adhere:

"*Well from the first day I met him is the day we both started medication here and became friends. I asked him how the drugs treat him, and he told me that it didn't treat him so bad apart from the dizziness, but for me, the drugs treated me badly, whenever I swallowed a pill, I would vomit, get a skin rash and every time I would go to the bathroom with diarrhea. He told me not to worry that I would be fine with time but encouraged me not to stop taking the drugs, and so I think if I had stopped swallowing the drugs, I would not be here now."(Adolescent boy below age 18)*

In the western part of Kenya adolescents attending Kakamega County referral Hospital, were recruited into a WhatsApp meant to foster peer support. The adolescents were able to share information regarding ART and other experiences resulting from medication. The initiative has improved adherence to ART. One member of the group was quoted saying:

"Adherence to treatment was a major problem among the 13- to 22-year-old age group, but this has greatly improved with the WhatsApp group."

A clinician working with APHIA*plus* Western project formed the WhatsApp group which is open to youth only between the ages of 13 to 22 years (Abwao, 2017). He attests that:

Adherence to treatment was a major problem among this age group, but this has greatly improved with the WhatsApp group. It is like a 24-7 therapy room. The good thing is that I am a member of the group, so if there is anything that is technical, I give advice even in the middle of the night."

Despite the importance of support groups, some respondents did not attend support groups at Murang'a CCC citing, distance (54%), being busy (15%) and bad timing (15%) as reasons. Geographical and economic access to care has been cited in several other studies. The shortage of money together with the long distance to the facility adversely affected adherence in South Africa among PLWHA. Respondents reported that their counterparts defaulted because of the time taken to refill pills (Chirambo et al., 2019). One participant stated that:

"*Money is a problem, even businesses are not going on well, so for someone who is not working but doing business only cannot manage every month to come for refill. Where is he/she going to*

find money for transport? Later they will start missing the appointments and then in the end will completely stop." (Male participant, adherent)

In many studies, distance to the health facility was shown to be major impediment to uptake of HIV services**.** One of the studies depicted association between distances to the health facility with higher self-reported adherence among the young people in Uganda(Bermudez et al., 2016). Being busy was also a commonly cited barrier to adherence by adolescents in South Africa(Kim et al., 2017). Overall, non-adherence may lead to drug-resistant HIV strains caused by inability to attain optimum viral loan suppression. Maximum medication adherence needs tracing of adolescents exposed to high susceptibility of non-adherence and focused strategies (Heestermans et al., 2016) This kind of evidence indicates that countries need to develop appropriate measures to assist ALHIV scale up adherence to ART. From literature leveraging mHealth can be a viable way to scaling up peer support without necessarily having to travel the health facility. Mobile phone connectivity in Kenya and availability of smart phones can be a good platform for peers to continue supporting each other hence improvement of adherence.

Conclusion.

From this study, the caregiver support from the family, peer and health facility visited seems adequate. However, reinforcement of care giver support and promotion of social support within families taking care of ALWHIV is fundamental in tackling ART adherence challenges among adolescents in Murang'a County**.** Adherence frameworks in the county, family and peer support groups are platforms for ALHIV exchange and participate in care. Considering the shortage in skilled human resources for health in Kenya support groups can contribute highly in care models, especially in adherence to ART.

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