Socio Cultural and Regimen Related Factors Influencing Adherence to Antiretroviral Therapy Among Youth (15-24 Years) in Selected Health Facilities in Nyeri County.

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Abstract

The number of youths living with HIV is rising globally. In Nyeri County, the prevalence of HIV is reported to be 5.1% and viral load suppression is 77.1%. Adherence continues to pose a serious challenge among the youth receiving antiretroviral therapy; barriers include dosing schedules, pill burden stigma, denial, lack of social support and drug adverse side effect. The study aimed at assessing the socio cultural and regimen related factors influencing adherence to antiretroviral therapy among youth (15-24 Years) in selected health facilities in Nyeri County. A descriptive cross sectional research design was adopted, 227 young people (15-24 years) living with HIV on antiretroviral therapy for more than 6 months were selected from Karatina district hospital, Nyeri referral hospital, and Tumutumu PCEA. Study sites were purposive sampled and the participants were sampled using probability proportionate to size. Quantitative data was collected using structured questionnaires while qualitative data was collected from two focused group discussion (FGD). Qualitative data was analysed using both descriptive and inferential statistical techniques, qualitative data was analyzed using thematic analysis approach. From the results, 115 were females while males were 112. Majority (159) were between the ages of 18-24 years, 215 were single with 155 having attained secondary school education. Most (221) had started medication before 15 years of age. Many (153) were virally suppressed, 135 were supported by the family and community, 96 had not experienced stigma and 151 had not denied their HIV infection status. Community, friends and family support, stigma, denial were significantly associated adherence to ART (<0.05). Regimen related results depicted that (61.8%) took 2 pills per day, 22.4 % more than 2 pills while 15.8 % took only one pill. Further, 29.1 % felt the drug burden while 18.5% reported side effects from the treatment. The number of pills per day was shown to be significantly associated with adherence (p=0.04). The study recommends concerted effort between the patients, family, community, health care providers and policymakers in Nyeri County to reduce stigma and denial. School management should create an enabling environment to help students take drugs regularly and privately. The Ministry of Education to develop strategies and guidelines as part of school-based support systems for HIV infected youth. Acceptance of status and disclosure necessitates good preparation through counselling and support to navigate ongoing challenges due to the lifelong treatment of the HIV. The county needs to strengthen Operation Triple Zero strategy in order to realize 90-90-90 UNAID targets.

Key words: ***Adherence, ART, Denial, Socio-cultural, Regimen, Pills, Stigma, Youth.***

Introduction

The number of young people (15-25 years) globally living with HIV is increasing and is reported to have worse clinical outcomes compared to all the other age groups. Currently, the number of AIDS-linked mortalities among the youth is reported to have risen by 30% while decreasing among all other age groups (United Nations Programme on HIV/AIDS, 2020). Furthermore, children infected with HIV perinatally transiting into adolescence and youth stage add to the burden of HIV in this particular age group (Reif et al., 2020). By the year 2019, 25.4 million people living with HIV were projected to be accessing antiretroviral therapy (ART) of which 88% were virally suppressed (United Nations Programme on HIV/AIDS, 2020). In the same year, 460,000 young people between 10 to 24 years were reported to be newly infected with HIV globally. In 2017, the total number of persons living with HIV (PLHIV) in Kenya was approximately 1.5 million, children below 15 years were 105,200 and those above 15 years were 1,388,200. The youth between the age of 15-24 years were 184,700 (12%) (National AIDS Control Council, 2018).

The goal of the National HIV program in Kenya is to have all people on ART be virally suppressed. In 2018, the Kenya Population-based HIV Impact Assessment reported the overall prevalence of HIV among adults to be 4.9%, while in Nyeri County it was 5.1%. Viral suppression was reported to be 56.4% in the country and 77.1 % in Nyeri county (National AIDS and STI Control Programme, 2020). As much as antiretroviral therapy (ART) is shown to be the best solution in the management for PLWHA, its effectiveness is reliant on consistent drug adherence and behavior. The higher the adherence level, the better the viral load suppression among patients (Yu et al., 2018). Estimates of ART adherence levels among the youth living with HIV in low income countries differ significantly. Furthermore, scanty information on adherence levels among in sub Saharan Africa still exist (Ridgeway et al., 2018).

Adherence is reliant on the entire process from choosing, medication initiation and maintenance and sustainability in care cascade. Non-adherence may result from missed dose, under dosing, overdosing, and drug breaks. Optimal adherence to ART leads to viral suppression and non-adherence can result to medication failure, rise in viral load, eventually leading to the increase in medication-resistant HIV genotype (Laisaar et al., 2013). Assessment of adherence behavior among patients can either be through drug event monitoring system, pill counting, prescription refill, and patient adherence reports system (Jima & Tatiparthi, 2018). Just like other drugs taken life long, attainment of desired levels of adherence to ART remains a challenge globally. Barriers mentioned include; pill burden, unawareness ART side-effects, disclosure, stigma, social support among others (Kioko & Pertet, 2017; MacCarthy et al., 2018a). Moreover, life as young person in Kenya, depression, substance abuse, poverty and lack of food are also cited as non-adherence factors in many studies (Micheni et al., 2017)

Globally, stigma and denial among the youth living with HIV remains a reality, and despite the concerted efforts by governments to fight it, PLHIV continue to suffer from it leading to poor clinical outcome resulting from non-adherence (Iacob et al., 2017). Studies have

reported denial as individual hindrances to adherence. A report from a study conducted in South Africa revealed denial among young adults who expressed anger in a focused group discussion over persistence of HIV from childhood through adolescence and into youth stage despite treatment adherence (Hornschuh et al., 2017). Social support from family members, the community and friends enables the youth to adhere to their ARV treatment. Family members act by reminding them about medication and even accompanying the sick to the clinics. The family is very important in meeting the basic provisions of the young people including monetary, clothing and food support. Peer support and networking is essential in HIV management and adherence to treatment guidelines among the youth living with the virus (Nabunya et al., 2020). In a study done by, Kioko & Pertet, (2017), 48.2% social support was perceived inadequate. This places emphasis on families and social support as a factor in attainment of optimal adherence to medication in among youths in Kenya.

Complexities from ART regimens contribute highly to non-adherence among the youth. Patients go through alterations or change of eating, sleeping patterns and daily life activities. Such changes subject the patients to frustration and a feeling that taking drugs is a heavy burden (MacCarthy et al., 2018a). Furthermore, prolonged medication, non-adherence among the youth is highly reported worldwide. For instance, in the same study by MacCarthy et al., (2018a), participants who were perinatally infected with HIV, expressed fatigue in taking drugs. Health providers also reported pill burden associated with 'drug holidays' among the youths. The side effects of ARV drugs among patients are frequent and severe, it includes symptoms nausea, vomiting, diarrhea, prolonged fatigue, headaches among other. Side effects experienced by the young people hinder adherence in a big way. In Sub Saharan Africa, ART side-effects is cited as the main to adherence alongside lack of social support(Ammon et al., 2018). Due to the challenges in adherence among the youths, the study aimed at assessing the socio cultural and regimen related factors influencing adherence to antiretroviral therapy among youth (15-24 Years) in selected health facilities in Nyeri County.

Materials and Methods

A descriptive cross sectional study design was used in 3 selected health facilities located in Nyeri County, Kenya. The study population included young people living with HIV aged between 15-24 years attending comprehensive care clinics (CCC) in the three facilities and had been on antiretroviral therapy for 6 months or more. A sample size of 227 HIV positive youth was used, determined using Fishers et al., (1998) formula. Purposive sampling was used to select the 3 facilities (Karatina district hospital, Nyeri referral hospital, and Tumutumu PCEA hospital). This selection was based on the fact that the facilities were high volume sites and had more than 50% of youths living with HIV attending the respective CCCs in Nyeri County. Further, probability proportionate to size was utilized to sample participants from each facility. The participants were selected by systematic random sampling from the line list. The first code was selected randomly and an interval of 2 (K=N/n) was used until the desired sample size was obtained. Participants for focused group discussion (FGD) were selected from the line list and included those who had not selected for the interview from the systematic random; the number obtained was then selected randomly to

form two focus group discussions of 8 to 10 participants. The FGD was held at Tumutumu Hospital (rural area) and another at Nyeri referral Hospital (urban area).

Quantitative Data was collected using an interviewer administered semi structured questionnaires while qualitative data was collected through focus group discussion, a moderator was present in each FGD and audio tape recorder was used to record all proceedings. Qualitative data was then analysed using both descriptive and inferential statistical techniques. Qualitative data was analyzed by thematic analysis approach according to the themes related to the research topic. Necessary ethical clearance and approval for the study were sought. Informed consent and assent were obtained, participation was voluntary, confidentiality and anonymity was also observed.

Results and Discussion

Among the 227 respondents that participated in the study, 115 were females while males were 112. Majority (159) were between the ages of 18-24 years, 215 were single with 155 having attained secondary school education. Most (221) of them started medication before 15 years of age. Amongst those who underwent viral load measurements to determine adherence, 153 (67.4%) showed undetectable levels of viral load (VL) while 74 (32.6%) were detectable. According to the World Health Organization, undetectable viral load of <1000 copies/ml is a pointer of adherence while a detectable viral load detectable > 1000 copies/ml indicates non-adherence (Yu et al., 2018). Viral Load testing is the recommended measurements in ART monitoring as compared to use the of clinical or immunological criteria. The CD4 count is a marker of immunological failure, a decrease results from viral multiplication (Laxmeshwar et al., 2020).

Socio- cultural factors associated with adherence

The results from socio cultural characteristics of the 227 respondents showed that, 120 (52.9%) had experienced stigma while 107 (47.1%) had not. Majority 74.9% reported to have had social support while only 20.7% socially avoided their peers. Additionally, 96% of the respondents never thought of stopping treatment. Many (95.2 %) reported to have not denied the fact that they were infected. Interestingly, among the 153 respondents who had undetectable levels of VL, 151 had indicated that they would never stop taking ART, 132 did not avoid friends, 135 were supported by the family and community, 96 had not experienced stigma and 151 had not denied their HIV infection status. Further, the results showed all the socio-cultural factors were significantly associated adherence to ART (<0.05) as shown in table 1 below.

Table 1: Association between socio cultural factors and adherence

		Frequency	Adherence N=153	Non-adherence N=74	Chi Square Statistic values
Should stop ART	Yes	9	2	7	X^2=8.706
	No	218	151	67	P=0.003
Avoidance of friends	Yes	47	21	26	X^2=13.925, P= 0.0001
	No	180	132	48	
Community or family support	Supported	170	135	35	X^2=8.147
	Not supported	57	18	39	P=0.0004
Stigma	Experienced Stigma	121	57	64	X^2 =49.811 P=0.0001
	No stigma	106	96	10	
Denial	Yes	11	3	8	X^2= 8.472
	No	216	150	66	P= 0.004

From the focused group discussions, fear of the unknown was mentioned to strongly contribute to stigma and discrimination among the participants. They further pointed out that they did not talk about their HIV status to anyone after they were diagnosed. However, at least the parents and guardians were privy of their status. Within the larger family, discussion on HIV never occurred, worryingly, the youths further expressed fear of possible rejection or judgement from the extended family or community if their status was known. From the discussion, youths expressed the fact that topics on HIV ought to be avoided. One of the participants was stated:

> *"When my mother died, I went to live with my grandmother, She was aware of my sero-positivity but her other children, my aunts and uncles, do not know it. I am afraid that if they find out, they will start discriminating against me"*

Further, another 16 years old participant reported to experience stigma and discrimination and had to hide his medication from his school mates since he studied in a boarding school. He was quoted saying;

> *"One day, I heard my classmate saying that those who have HIV have undergone God's punishment. Since then I have been hiding my medicines and I am afraid one day I will be caught taking them"*

Fear of rejection, discrimination and stigma from the study was shown to be a hindrance to adherence to medication among the youths interviewed in Nyeri county. The fact that majority were school going, being in a boarding set up where privacy is a challenge, adherence to medication was seen to be hindered. This situation would force the youths to seek care from distant health facilities or even stop taking medications when in the presence of their peers in school. Hindrance to adherence among the youth in a boarding school setup was also confirmed in study done in Uganda. The report indicates that school attendance hindered privacy which resulted to disruption of ART adherence (MacCarthy et al., 2018b).

From the table above, family and community support was demonstrated to significantly influence adherence. The results from this study corroborates with those from other earlier studies done in sub-Saharan Africa where peer, family or community social support were cited as essential for ART adherence among young adults. For instance, a studies done in Kenya, Uganda, Mozambique, Rwanda and Tanzania among HIV positive youths showed that attrition in those who were initiated on ART was lower in HIV clinics that offered social support. It further affirmed the importance HIV support group and sufficient parental/monitoring support. The reports asserted that support was closely linked with decreased non-adherence among young people in South Africa (Brown et al., 2017; MacCarthy et al., 2018).

Family members and peers provide support to by assuming the responsibility of reminding the sick persons about medication, clinic visits and also escorting to the health facility. Family members are significant in providing monetary, clothing and food support (Nabunya et al., 2020) From the focused group discussion, the young adults pointed out that family and social support was important for the wellbeing of HIV patients. They added that care from health providers, family and HIV support groups were important in fighting stigma. Even so, some of the respondents reported to not receive adequate social support and this hindered taking of medications. One of the participants stated;

> *"At home, I have my mom who reminds me every day to take medication. But when I am at school I do not have anyone to remind me because nobody else knows"*

Trust and confidence of the youth in care is reliant on patient-health worker relationship, which then impacts ART uptake, access to care and on overall adherence (Croome et al., 2017). The importance of the health care facility more so the health care providers in providing support to the youths was demonstrated when some of the respondents confirmed the support they received from Nyeri County Hospitals. A participant expressed that;

> *"I manage to get good adherence because of the support of my doctor. The medical team helps us a lot and cares about our health. When I do not come to my clinic appointment, they call me to inquire about my situation or a social worker comes to visit me at home. I thank them very much because if it was not them, I would already be dead*"

Use of support groups in South Africa among young people living with the HIV has been documented to be useful in increasing and reinforcing adherence of patients living with HIV.

Moreover, when mobile health was used to test improvement in adherence among HIV positive adolescents, it proved to be effective in increasing adherence among young people. Additionally, the study report indicated that peer to peer support group was thought to create a favorable environment for positive behavior change. This was because the participants reminded each other to take medication, shared how to tackle medication adverse effects and encouraged each other on how to live normally. The output from that study depicted an improvement (6.8%) from social support, decline in stigma and increased adherence from self-reporting (de Jager et al., 2018). From the discussion in the current study, respondents confirmed that peer support was important in adherence. Some of the respondents contributed that;

> *"The support groups allow me to meet other young people living with HIV and to compare our experiences of sero-positivity to share the difficulties encountered with the drugs. At least I know that I am not the only one to endure the burden of HIV"*

They were also quoted saying;

> *"When we talk in groups, it helps us enormously. We learn how to deal with certain situations that can come under the status of sero-positivity like stigma, rejection and that encourages us and gives us the strength to keep going"*

Among those who had were non adherent in the study, majority (67%), reported to have stopped taking medication. Continuation of medication was also shown to significantly influence adherence in the study. From the discussion, the youths pointed out non adherence was brought about by denial. Some did not accept to be HIV positive and others believed that infection with HIV would fade away. Additionally, others said that the disease was curable and that in future they would stop medication. One of the youths expressed frustrations from being HIV positive, the respondent was quoted saying;

> *"I wonder why me? Because the worst part is that I am the only one living with HIV in a family of four persons. I don't understand why I have to take medicine all my life. My uncle tries to help me but sometimes I do not really want to take this drugs and I lie that I took when not"*

Another one contributed that;

> *''When I feel good, I think I no longer have the virus and I stop taking the drugs. The problem is that I get sick sometimes even until I am hospitalized''*

Denial of HIV status and the urge to stop medication are important determinants of adherence which should be taken in to consideration by the Nyeri County from the time a patient is enrolled in care. As recommended by many other studies, it is critical for the health care system in Kenya to recognize the barriers to adherence in medication faced by the youth face, this would enable development and implementation of youth friendly strategies that would strengthen and improve clinical outcomes in all levels of HIV care continuum . Sustainable modalities to boost family, community and social support, such as peer networks are essential.

ART regimen related factors associated with adherence.

The respondents were asked to specify how many pills they swallowed per day, if they felt the drug burden and if they experience side effects from the drugs. Majority (61.8%) took 2 pills per day, 22.4 % took more than 2 pills while 15.8 % took only one pill. Out of the 227 respondents, 29.1 % indicated that they felt drug burden while 70.9% reported otherwise. Side effects from the treatment were reported by only 18.5% while 81.5% of the respondents indicated not experiencing side effects.

Table 2: Association between ART regimen factors and adherence

		Frequency	Adherence N=153	Non-adherence N=74	Chi square Statistic values
Pill per day	1 pill	36	26	10	$X^2 = 0.0816$
	2 Pills	139	105	34	P= 0.04
	>more	52	22	30	
Feel pill burden	Yes	66	42	24	$X^2 = 0.594$
	No	161	111	50	P= 0.441
Side effects	Yes	42	24	18	X^2= 0.0816
	No	161	129	56	
					P= 0.122

As shown in the table 2, among the 153 participants who were adherent to medication, 105 took 2 pills per day, 111 reported no pill burden and 121 felt no side effects to ART. The number of pills per day was shown to be significantly associated with adherence (p=0.04). Pill burden and side effects was not statistically associated with adherence (p>0.05). From the study conducted by MacCarthy et al., (2018) in Uganda, hindrance to adherence resulted from the burden of taking many medications every day, this was cited as a frustration by the youth hence leading to what is known as ‘ drug holiday’. From the group discussion held, the respondents expressed that they missed taking drugs daily because they felt they were many. One of the girls on the 2nd line ART treatment regimen stated that;

> “*I have 6 tablets to swallow per day. Sometimes I feel overwhelmed by these pills and I only take half of it just to get some rest. ”*

Similar to these findings, experiences shared by the youth in in Soweto, South Africa showed that the number of pills and the feeling it is a burden hindered adherence. The respondents stated that they felt fatigued or bored ARVs every day. Others felt that the drugs was too much work, were big in size and had awful taste and that it was better if it was in syrup form (Hornschuh et al., 2017).

Side effects from the drugs were reported in the discussion, it was pointed out to be a contributor to non-adherence among them. One of the respondents stated that;

> "*Before the drugs caused diarrhea and bowel problems. The next day I would stop them and take them back when I felt better. But thank God the doctor changed the regimen now it is better*"

From this study, it is evident that drug related adverse effects, pill burden and daily medication are vital for adherence which necessitate development of regimens that are easy to adhere to Studies have shown that weekends off ART may assist maintain infected youths on lifelong ART treatment. Such regimens are non-inferior and one tablet regimens have been demonstrated to be effective with remarkably a higher VL suppression rates than multi-tablet regimens (Turkova et al., 2018). Drug related strategies executed in parallel with health services interventions could considerably and sustainably influence youth adherence to ART (Reif et al., 2020).

Conclusion

The results from this study depicted social support to be hindrance to adherence to ART yet it was shown to significantly influence adherence. There is need for concerted effort between the patients, family, community, health care providers and policymakers in Nyeri County to reduce stigma and discrimination. In boarding schools, management should create an enabling environment to help students take drugs regularly and privately. The Ministry of Education should develop strategies and guidelines as part of school-based support systems for HIV infected youth. Acceptance of status and disclosure necessitates good preparation through counselling and support to navigate ongoing challenges due to the lifelong treatment of the HIV. As youth become sexually active, they the responsibility of disclosing their HIV status to their companions, these requires them to be equipped with specific skills to aid them handle the often complex social and sexual dynamics. The county needs to strengthen Operation Triple Zero strategy in order to realize 90-90-90 UNAID targets in young adults. Operational research evaluating combination interventions to improve adherence needs to be undertaken in the county since no individually directed approaches have been demonstrated significantly influence adherence.

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