

Retention in HIV Care and Associated Factors Among Youths Aged 15-24 Years in Rural Southwestern Uganda

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Abstract

Background: Retention in HIV care contributes to antiretroviral therapy adherence, which is a key factor for improved treatment outcomes and prevention of drug resistance. However, HIV treatment among the youths is characterized by loss to follow up, poor adherence to ART, risk of treatment failure and high mortality rates compared to young children and adults. There is limited information about factors contributing to poor retention of youths in rural settings in Uganda. We aimed to determine the extent of retention in HIV care, level of and associated factors among youths aged 15-24 years in rural southwestern Uganda.

Methods: A cross-sectional study was conducted among youths aged 15-24 years who were receiving care at the HIV clinic at Kabuyanda HC IV who had been in care for at least 1 year before the study. We used a researcher administered questionnaire to collect sociodemographic information and retention. We collected information on HIV related stigma using the 40-item Berger Stigma Scale. We used the SPSS chi-square test and regression analysis assess the association between predictors and retention HIV care, at 95% level of confidence and at a level of significance of 0.05. Retention in HIV care was, defined as having sought care at least once per quarter in the 12 months prior to the study.

Results: We enrolled 102 participants with mean age of 20.95 (SD±3.07) years. Two thirds (65.7%) of the youths had been retained in HIV care in the previous 12 months. Retention in HIV care was significantly associated with female gender (AOR: 0.15, 95%CI 0.03-0.69, p=0.015), being a 'Mukiga' by tribe (AOR: 5.77, 95%CI 1.76-18.91, p=0.004) and being married or in a relationship (AOR: 0.18, 95%CI 0.06-0.53, p=0.002). The association between HIV related stigma and retention in HIV care was non-statistically significant.

Conclusion: Retaining adolescents and young adults in HIV care in rural southwestern Uganda is still much lower than the WHO target of 90%. Being female and married or in a relationship are associated with good retention in HIV care. Interventions targeting adolescents and young adults are necessary to improve retention in HIV care to the WHO target of 90%.

Background

HIV is a global challenge despite several years of several researches, interventions and HIV services. Retention in HIV care is essential and provides opportunities to monitor response to therapy, prevent associated complications, and deliver ancillary services (1). Retention in HIV health care services is a critical precursor to antiretroviral therapy (ART) adherence and viral suppression (2). To prevent considerable HIV related morbidity and mortality, all HIV-positive persons must be put on ART and should remain in care to achieve virologic suppression (3). According to the UNAIDS 90-90-90 strategy, 90% of those enrolled into HIV care should be retained. However, this has not yet been achieved in many settings and sub-populations including adolescents and young adults (4, 5). Few HIV positive youths below 25 years are retained in care after initiation of ART (6-8). The poor retention in HIV care could be due to

social, structural or health related factors such as stigma and discrimination, distance and transport to the health facility, poverty and unemployment, work/child care responsibilities, and social relations as major determinants of retention in care (9). A recent study by Izudi and colleagues (2018) in central Uganda found that approximately 70% of adolescents were non-retained in care at Katooke Health Center, mid-western Uganda (10). Poor retention in care has been associated with duration on ART and adolescent age, with older adolescents (15–19 years) having poorer retention in HIV care compared to younger adolescents aged 10–14 years (11). Yet, suboptimal retention is associated with poor ART adherence and suboptimal virologic non suppression which worsen health outcomes (12, 13). This in turn leads to increased HIV associated morbidity and mortality, and poor quality of life (14).

Previous studies in low and middle-income countries have observed that factors influencing retention in care are similar to those that influence adherence to ART (15, 16). Factors associated with retention in HIV care have been categorized into individual, political, socio-economic, stigma and discrimination, sociodemographic and health system factors (17). In Zambia, a mixed study to examine barriers to retention in HIV care of HIV positive adolescents identified multiple factors including stigma and discrimination, poverty, disrespectful treatment from clinicians, their individual adolescent-specific responsibilities (e.g. school), and cultural beliefs and traditions about illness (18). However factors associated with poor retention in ART services in youths aged 15-24 years residing in rural settings of low income countries have not been explored. Therefore, we aimed to determine retention rate and associated factors among HIV positive youths aged 15-24 years enrolled for HIV care in rural southwestern Uganda.

Methods

Study design & site.

We conducted a cross-sectional study at an HIV clinic at Kabuyanda Health Centre IV in Isingiro district from July 2020 to August 2020. The health facility is located 108 Km south of Mbarara city. Kabuyanda HC IV is the only public health facility in the area that offers HIV care services. The adult HIV clinic operates two days a week (Wednesday and Thursday) for Antiretroviral Therapy (ART) refill appointments but the adolescent HIV clinic operates every last Thursday of the month. The clinic serves about 1200 of HIV clients of whom 112 are youths aged 15-24 years. Isingiro district was selected for this study due to its young population: 57.2% aged 0-17 years and 17.3% aged 15-24 years (19). The study area is a rural community with households earning their livelihood through subsistence farming and cattle keeping.

Study participants

We enrolled 102 youth aged 15-24 years living with HIV who were accessing care at Kabuyanda Health Centre IV and had been in care for at least one year. The sample size was determined using Krejcie-Morgan Formula (20) using the 90% retention in care among the youth as determined in a previous study in Uganda (21).

Sampling and data collection

A list of potential participants was generated by the data clerks and the HIV counsellor at the facility contacted the participants by phone calls, and referred them to the research team at the facility who assessed their eligibility to participate in the study. Those who met the inclusion criteria, study aims were explained to them in their local language, and were given a chance to ask questions for clarification. All eligible participants gave written informed consent to participate in this study. Participants below 18 years assented and their care givers provided written informed consent. A consecutive sample of youths aged 15-24 years who consented to participate in the study were recruited.

Study variables

Retention in care

Retention in care was defined as having attended at least 4 visits in 12 months prior to this study with at least 1 visit each quarter. The proportion of youths aged 15-24 years retained in care, was obtained basing on the 3-month visit constancy method, among the methods described by Charles and colleagues (22). We reviewed medical records of 12 months prior to the study. The 12 months were divided into four equal quarters and the number of visits in each quarter was recorded. Each medical file was assigned a code to ensure confidentiality.

Socio-demographic and disease characteristics

A well-designed interviewer administered questionnaire was created to explore factors that influence retention in HIV Care. The tool was also designed to capture the sociodemographic information including; age, gender, occupation, marital status, living arrangement, duration on treatment, ART regimen, HIV acquisition and HIV disclosure status.

HIV Berger Stigma Scale

HIV-related stigma was measured using the Berger HIV Stigma Scale (23), which is a validated and standardized to measure stigma experienced by people living with HIV. It contains 40-items scored on a 4-point Likert-type scale (strongly disagree, disagree, agree, strongly agree) with total stigma scores ranging from 40 to 160. The scale measures 4 stigma subscales; (1) personalized stigma (assessed by 18 items) measuring consequences of people knowing ones HIV status including rejection by others, loss of close friends, (2) disclosure concerns (assessed by 10 items) which measure the likelihood that one will tell others about their HIV diagnosis, (3) negative self-image (assessed by 13 items) assessing individual's feelings about themselves, (4) concern with public attitudes (assessed by 20 items) which measures participants' public's perceptions of attitudes towards persons living with HIV(23). Higher scores indicate a greater level of agreement with each item, and the severity of stigma.

Data collection

The Interviewer administered questionnaire and the Berger stigma scale were administered in the same interview with each participant. The duration of the interview was approximately 35-45 minutes.

Interviews were conducted in a doctor's room at the health facility to ensure privacy and confidentiality of patients' information. Participants who required post-interview counselling were referred to the facility counsellor after the interview.

Data management and analysis

At the end of every interview, the questionnaires were reviewed for completeness. The research team ensured that patient charts were de-identified and reviewed only once. Filled questionnaires were kept in a lockable cupboard to ensure data safety. Data entry forms were prepared in Microsoft excel 2013 where data were entered in duplicate to avoid errors. Entered data was saved and stored on a pass-word protected computer that was only accessed by the research team members. A copy of same data set file was saved on a Flash disk stored by the principal investigator, as a back-up file. After data cleaning, data were imported into the IBM SPSS Statistic 20 for analysis.

Data analysis

Continuous variables were described using frequencies and percentages, ranges, means with standard deviations and p-values. Retention in care was calculated as the proportion of youths aged 15-24 years who sought care from Kabuyanda HC IV at least once quarter in the 12 months prior to the study out of the total number of participants. Age of participants was stratified into adolescents (15-19 years) and young adults (20-24 years). The total Berger stigma scale score and sub-scores of individual forms of stigma, were obtained by adding Likert scores for individual items in the scale. Due to lack of a universally accepted cut point of the scores, we adopted the categorization put forward by Charles and colleagues (2012) in which the overall stigma scores were categorized into three categories as: no/mild, moderate, and severe stigma using the 33rd and 66th percentile cut off values from the distribution of scores (22). From this, we obtained proportions of youths experiencing different levels of stigma. Considering the possible stigma scores for total stigma and the categories, participants who scored below 33rd percentile of the stigma scale, were considered having no/mild stigma, those scored between 33rd and 66th percentile had Moderate stigma, and those above whose scores are above the 66th percentile, had severe stigma. The proportion of participants with stigma was calculated as the total participants with moderate or severe stigma out of the total number of participants. The proportion of participants with different dimensions of stigma was calculated as the total participants with moderate or severe specific stigma dimension out of the total number of participants.

At bivariate analysis, we analyzed categorical variables using cross tabulations, Crude Odds Ratios (COR), chi-square test, and p-value to assess for association between the socio demographic and clinical variables (age, gender, tribe, occupation, marital status, geographical location, and disclosure status, living situation), HIV related stigma and the likelihood of retention in care. All covariates that were associated with the outcome variable with a $P < 0.3$, were included in the multivariate regression model to determine the independent factors using the Adjusted Odds Ratios (AOR) with 95% C.I, with 95% confidence interval, and level of significance at p value < 0.05 .

Results

Socio-demographics and disease characteristics

Of the 102 participants recruited, the Mean age was 20.95 (SD±3.07) ranging from 15 to 24 years. Majority of the participants (77.5%) were females, 74.5% aged 20-24 years, and 69% had attained primary level of education (Table 1).

Table 1: Socio-demographic and clinical characteristics of Youths aged 15-24 years receiving ART Care (N-102)

Characteristics	Categories	n (%)	Sought care at least once in each quarter in 12 months		Chi-square test	P value
			Yes n (%)	No n (%)		
Age (years)	15-19 years	26 (25.5)	18 (69.2)	8 (30.8)	0.195	0.66
	20-24 years	76 (74.5)	49 (64.5)	27 (35.5)		
Sex	Female	79 (77.5)	47 (59.5)	32 (40.5)	5.96	0.015
	Male	23 (22.5)	20 (87.0)	3 (13.0)		
Tribe	Mukiga	65 (63.7)	36 (55.4)	29 (44.6)	8.44	0.004
	Munyankore	37 (36.3)	31 (83.8)	6 (16.2)		
Marital status	Married	37 (36.3)	28 (75.7)	9 (24.3)	2.57	0.11
	Unmarried	65 (63.7)	39 (60.0)	26 (40.0)		
Level of education	None	17 (16.7)	11 (64.7)	6 (35.3)	0.03	0.99
	Primary	71 (69.6)	47 (66.2)	24 (33.8)		
	Secondary	14 (13.7)	9 (64.3)	5 (35.7)		
Geographical location	Kabuyanda SC	49 (48.0)	33 (67.3)	16 (32.7)	2.448	0.49
	Kabuyanda TC	15 (14.7)	12 (80.0)	3 (20.0)		
	Kikagati SC	26 (25.5)	15 (57.7)	11 (42.3)		
	Other	12 (11.8)	7 (58.3)	5 (41.7)		
HIV status Disclosure	No	17 (16.7)	9 (52.9)	8 (47.1)	1.47	0.23
	Yes	85 (83.3)	58 (68.2)	27 (31.8)		
HIV Acquisition	Born with HIV	19 (18.6)	17 (89.5)	2 (10.5)	5.86	0.02

	Acquired it Later	83 (81.4)	50 (60.2)	33 (39.8)		
Total stigma score	No/Mild	1 (1)	1 (100)	0(0)	0.79	0.67
	Moderate	41 (40.2)	28 (68.3)	13 (31.7)		
	Severe	60 (58.8)	38(63.3)	22(36.7)		
Personalized stigma	No/Mild	2 (2)	1(50.0)	1(50.0)	1.499	0.47
	Moderate	48 (47.1)	29(60.4)	19(39.6)		
	Severe	52 (51)	37(71.2)	15(28.8)		
Disclosure concerns	Moderate	29 (28.4)	20(69.0)	9(31.0)	0.193	0.66
	Severe	73 (71.6)	47(64.4)	26(35.6)		
Negative self-image	Moderate	53 (52)	36(67.9)	17(32.1)	0.245	0.62
	Severe	49 (48)	31(63.3)	18(36.7)		
Public attitudes	Moderate	38 (37.3)	24(63.2)	14(36.8)	0.172	0.68
	Severe	64 (62.7)	43(67.2)	21(32.8)		

Legend: ART-Anti retroviral therapy, HIV-Human immunodeficiency virus, TC – Town Council

Level of HIV related stigma

The overall stigma scores ranged from 41 to 154 with mean score of 112.25 ± 21.77 (95% CI: 107.92, 116.48). The mean scores for the 4 stigma subscales were; personalized (49.03 ± 10.39), disclosure concerns (29.71 ± 5.53), negative self-image (34.60 ± 7.01), and public attitudes (56.60 ± 11.15) (**Table 1**). According to total stigma scores, 58.8% were severely stigmatized, 40.2% experienced moderate stigma and only 1% had no stigma. Majority of the participants experienced severe stigma related to disclosure concerns (71.6%), and comparatively lower stigma related to negative self-image (48%). None of the participants experienced no/mild stigma related to disclosure concerns, negative self-image or public attitudes.

At bivariate analysis, gender and tribe of the participant were significantly associated with retention in HIV care at Kabuyanda HC IV. Being a female (COR=4.54, 95% CI 1.25-16.56; P = 0.015), and a Mukiga (by

tribe), (COR=0.24,95% CI 0.09 – 0.65; P = 0.004) and being born with HIV (COR0.18, 95% CI 0.04-0.82; P = 0.02) were associated with good retention in HIV care at 95% level of confidence. HIV related stigma did not show a significant relationship with retention in HIV care (Table 2). Covariates with a P< 0.3, were analyzed by regression analysis. The results of multivariate regression analysis of gender, tribe, disclosure status, HIV acquisition, marital status and personalized stigma are presented in Table 2.

Table 2: Bivariate and Multivariate regression analysis of factors associated with retention in HIV care of youths aged 15-24 years (N=102).

Characteristics	Variable	Crude OR (95% CI)	P value	Adjusted OR (95% CI)	P value
Gender	Female	4.54 (1.25-16.56)	0.022	0.15(0.03-0.69)	0.015
	Male				
Tribe	Mukiga	0.24 (0.09 – 0.65)	0.005	5.77(1.76-18.91)	0.004
	Munyankore				
Marital status	Married	2.07 (0.84- 5.10)	0.11	0.18(0.06-0.53)	0.002
	Unmarried				
Disclosure status	No	1.91(0.66-5.49)	0.23	0.62(0.18-2.19)	0.46
	Yes				
HIV Acquisition	Born with HIV	0.18(0.04-0.82)	0.03	5.47(0.94-31.76)	0.06
	Later				
Personalized	Moderate	1.61(0.75-3.44)	0.22	0.03(0.001-1.04)	0.05
	Severe			0.52(0.19-1.41)	0.20

Discussion

This study aimed to determine retention rate, HIV-related stigma and associated factors among youths aged 15-24 years enrolled at Kabuyanda HC IV in Isingiro district, southwestern Uganda. We found that 65.7% of the youths sought care at least once in each quarter in previous 12 months (retention in HIV care) prior to the study. Gender, tribe, and marital status were significantly associated with retention in care. HIV related stigma did not have a statistically significant relationship with retention in care among our participants.

The level of retention in HIV care in our study is much lower than the UNAIDS target of 90%, but similar to that reported in other studies done in Uganda by Okoboi et al (2016), who found a rate of 65% among Ugandan adolescents aged 10-19 years (24). However, the retention rate of 65.7% in our study is much higher than 29.3% that was reported by Izudi et al (2018) in central Uganda (10).

Our findings on retention in HIV care are lower than those reported by Nabukeera et al (2015) in their study to establish adherence to antiretroviral therapy and retention in care for adolescents living with HIV from 10 districts in Uganda who reported a retention rate of 90% (21). The difference may be due to differences in the characteristics of the study sample. While the study by Nabukeera et al (2015) recruited adolescents only (10-19 years), we recruited both adolescents (15-19 years) and young adults (20-24 years) (21). The retention rate in our study is also lower than that of Brown et al (2017) among youths 15-24 years in rural Kenya where 81% of these youths had been retained in HIV care at 1 year (25).

According to our study, being female was associated with high retention in HIV care compared to the males in the same age group. This compares with a similar study by Takarinda and colleagues (2015) in Zimbabwe which showed that men were retained in HIV care services for only a few months compared to women (26). Different factors that promote retention of women and girls living with HIV in HIV care were, peer support especially from trained and supervised mentor mothers, delivering of an integrated mother infant package, ART specific counseling at the initiation of ART, as stated in a study by Rollins et al (2017) (27).

Similarly, in a study by Nabaggala, (2018) in Uganda, women were more likely to return to care after active tracking compared to men (28). There is evidence that men disengage from care more frequently (29). These findings suggest that specific interventions targeting men and boys should be put in place to improve their retention in HIV care. Therefore, whereas majority of efforts have been invested in improving the quality of life of HIV positive girls and young women, special attention is urgently needed to address the issues related to retention in HIV care for males.

Marital status for both men and women was significantly associated with retention in HIV care in our study. Our findings are similar to those reported by Umeokonkwo et al (2019) in Anambra state in Nigeria in which marital status was a significant predictor of retention (30). Being married, or having a spouse provides a source of psychological and emotional support which improves retention in care compared to those who are single and not in a relationship. In a study by Santos et al (2018) to determine the source of social support of people with HIV, the main source of physical, emotional and social support were spouses/partners (31). However, a study about predictors of retention in HIV care among youth (15–24 years) in a universal test-and-treat setting in rural Kenya, they didn't find any association between marital status and retention (25).

Limitations

This research was conducted during country lockdown following a COVID-19 pandemic that could have affected retention due to tension with in the general public about acquisition of the virus.

The “3 months visit constancy method” used to determine stigma did not cater for those who had been given drugs for more than one month especially schooling students, but never the less, we were able to get their information from the ART refill book with the aid of the facility ART Clinic in-charge.

The Berger Stigma Scale used to assess stigma was first used in adult population. However, we had a few participants aged below 18 years, and most participants were above 18 years.

Conclusion

Youths aged 15-24 years are still poorly retained in HIV care in rural southwestern Uganda despite the efforts put in place by the ministry of health to improve HIV care. . Being male and unmarried seems to have the greatest risk for poor retention.

Recommendations:

We recommend interventions specifically targeting adolescents and young adult males to improve retention in HIV care especially in rural settings. There should also be additional focus on improving social and emotional support to optimize retention in care among youths (15-24 years).

List Of Abbreviations

ART Antiretroviral therapy

HC IV Health Centre Four (IV)

HIV Human Immunodeficiency Virus

UBOS Uganda Bureau of Statistics

Declarations

Ethics approval and consent to participate

The study was reviewed and approved by the Research Ethics Committee of Mbarara University of Science and Technology (MUST REC 20/01-20). The Uganda National Council of Science and Technology (UNCST) gave the regulatory clearance to conduct the study in Uganda (RESCLEAR/01). Administrative clearance to carry out the study at the facility was granted by the District Health Officer of Isingiro district, and the In-Charge of Kabuyanda HC IV. Unique identification participant codes were used to identify participants hence, no participant identifiers were captured at data entry to ensure their privacy

and confidentiality. Written informed consent was obtained from all participants as well as verbal assent for participants aged <18 for whom the care takers provided written consent.

Consent for publication

The participants provided consent to participate in the study and for publication.

Availability of data and materials

All the data needed for this manuscript has been included. In case there is need for clarifications, the corresponding author can be contacted.

Competing interests

The authors have no competing interests.

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Authors' dded a few limitations that need review and editst participants were students,contribution

LAP conceived the idea, supervised concept writing, and protocol writing. AKS participated in concept development and protocol writing. KV participated in concept development and writing, protocol writing, and data collection. SE participated in concept development and writing, protocol writing, translation of study tools, data collection, review and editing the original manuscript draft.

AE participated in concept development and writing, protocol writing and translation of study tools.

MM participated in concept development and writing, protocol writing, supervised data collection and analysis, developed the first draft of the manuscript, review and editing the original manuscript draft.

HML and GZR mentored the team and participated in writing, reviewing and edit the manuscript draft. SA contributed to the review and revision of the manuscript. All authors reviewed and approved the final manuscript for publication.

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