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ORIGINAL PAPER

Facilitators and Barriers to Adherence to Antiretroviral Therapy and Retention in Care Among Adolescents Living with HIV/AIDS in Zambia: A Mixed Methods Study

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Abstract

Little is known about the factors that contribute to the losses during stages of the HIV continuum of care (CoC) and specifically during the latter stages of antiretroviral (ART) adherence and retention in HIV care among adolescents living with HIV/AIDS (ALHA) in sub-Saharan Africa. We conducted a mixed-methods study: six focus group discussions with 43 ALHA (age 17–19); in-depth interviews with four (age 18–19): and survey-based interviews with 330 ALHA (age 18–19) to identify, understand, and describe factors contributing to the losses in the latter stages of the CoC among ALHA in Zambia. Through focus group discussions and in-depth interviews, ALHA identified barriers at the intrapersonal level (e.g., poverty; lack of adequate nutrition; fear of stigma), interpersonal level (e.g., stigma; disrespectful treatment by providers), institutional/facility level (e.g., lack of adolescent specific services), and community level (e.g., lack of collaboration among organizations; social norms). In quantitative interviews, we found that 46% (101/220) of ALHA reported missing any clinic appointments in the past three months, and about 19% (41/221) reporting missing one or more doses of ART in the last week. Logistic regressions indicate that walking to the site of appointment and being currently employed were predictive of missed visits. Findings highlight the complexity of the multiple factors that are unique to ALHA in Zambia, which should be addressed to improve adherence to ART and retention in HIV.

Keywords Adolescents · Adherence · Retention · Continuum of care · Zambia

Introduction

In December 2013, UNAIDS announced the ambitious Fast-Track targets for HIV treatment scale-up: by 2020, 90% of all people living with HIV will know their HIV status; 90% of all people with diagnosed HIV infection will receive antiretroviral treatment (ART); and 90% of all people receiving antiretroviral therapy will have viral suppression [1]. The Zambian government has accepted this challenge by issuing new guidelines that state that all infants and children that attend inpatient or outpatient care, immunization clinics, and nutrition clinics, as well as all sexually active adults, should be routinely tested for HIV [2]. If positive, adolescents should be started on ART immediately, irrespective of clinical stage or CD4 count [2].

However, gaps in the provision of and access to services for adolescents living with HIV/AIDS (ALHA) in Zambia pose a major barrier to the country's attainment of the 90–90–90 goal. [3] Success of HIV programs depends on the progression through a number of stages of the continuum

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of care (CoC): HIV testing and counseling; linkage to care; ART eligibility assessment and clinical staging (including CD4 testing); ART initiation and long term ART adherence and retention in care (Fig. 1). [4] In Zambia, as in elsewhere is sub-Saharan Africa, there are substantial losses at each stage of the continuum, with particularly high losses during the ART and retention in care stage of the CoC [5, 6]. In Zambia, the loss to follow up on ART for people living with HIV/AIDS ranges from 13 to 36% [8, 9]. Key barriers affecting retention in care among people living with HIV/AIDS include stigma, distance to care facility, transportation costs, and poverty [10, 11].

Adolescents fare poorly along the CoC compared to other age groups [1]. Only 42% of Zambian adolescents and young adults (age 15–24) are aware of their HIV status, 72% are on HIV treatment, and 71% of those are virally suppressed [7]. Though there is limited adolescent-specific data on adherence in low- and middle income countries (LMICs), ART adherence is estimated to be between 62% and 77% for ALHA, lower than other age groups, putting ALHA at any increased risk for uncontrolled viral load and subsequent opportunistic infections [12–16]. A recent systematic review focused on correlates of adherence among ALHA in LMICs highlighted the following key risk factors for suboptimal adherence: adolescent-related factors (i.e. male sex, being sexually active, being a double orphan, having stunted growth); caregiver-related factors (i.e. widowed caregiver, low caregiver involvement, low caregiver education level); medication-related factors (i.e. intolerance to medication, having a high number of ART medications); and environmental, social, and health care-related factors (i.e. living in an urban area, having missed clinic appointments) [14]. However, many of these factors, such as sex, have been significantly but inconsistently associated with suboptimal adherence, indicating that little is known about barriers contributing to losses among ALHA during the latter stages of the CoC: ART initiation, ART adherence, and retention in care [11, 14, 16].

We conducted a cross-sectional study using quantitative and qualitative data collection methods and analyses to identify, understand, and describe barriers, facilitators, and areas of improvement for ALHA in Zambia. This mixed-methods approach was appropriate to use for a comprehensive understanding of factors that affect adherence to ART and retention in care among ALHA. Quantitative data were utilized for insights on factors affecting retention for a larger population of ALHA, whereas qualitative data were utilized for ALHA personal experiences pertinent to those factors. This study was conducted by Boston University School of Public Health (BUSPH) and the Zambian Centre for Applied Health Research and Development (ZCAHRD) Limited as part of the Zambia Rising project funded by the United States Agency for International Development (USAID) and implemented by Save the Children Zambia [18]. The larger project enrolled ALHA and mothers of HIV-exposed infants and children who were administered two separate quantitative questionnaires. Our analyses presented herein focus on ALHA. We examined factors operating at multiple levels of the social ecology (intrapersonal, interpersonal, institutional (i.e. facility), community) which affect ART initiation, ART adherence, and retention in care [17]. Determining the multilevel factors affecting these three stages of the CoC is critical in informing Zambia's strategies towards attainment of the UNAIDS 90–90–90 targets.

Qualitative Study on Factors Affecting Art Initiation, Adherence, and Retention in Care for ALHA in Zambia

Qualitative Methods

Qualitative Sample, Sample Recruitment, and Data Collection Methods

The qualitative portion of the study included 47 ALHA (See Table 1) from six HIV clinics across three study districts: George Clinic, Kalinglinga Clinic, Chawama Clinic, and Chipata First Level Hospital in Lusaka; Chiwempala Clinic in Chingola; and New Masala Clinic in Ndola. Clinics were purposely selected given the high HIV prevalence and burden [2, 16]. ALHA retained in care at the time of the interview at these districts and HIV clinics were approached using a reference-based sampling method; ALHA were referred to the study by health and social service providers.

A total of six focus group discussions (FGDs) were conducted, each involving between 6 and 9 ALHA and lasting for an hour, on average. A total of four in-depth interviews

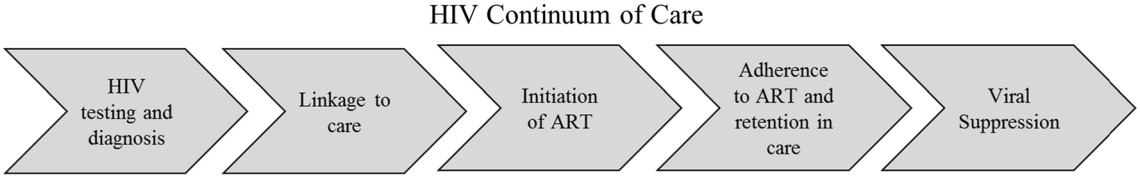

Fig. 1 HIV Continuum of Care [4]

Table 1 Focus group and in-depth interview data collection (N = 47)

Variable	Focus group discussions (n = 43)	In-depth interview (n = 4)
	% (n)	% (n)
Age (years)		
17	9.3 (4)	0 (0)
18	39.5 (17)	50.0 (2)
19	51.2(22)	50.0 (2)
Gender		
Male	62.8(27)	50.0 (2)
Female	37.2 (16)	50.0 (2)
District		
Chingola	18.6 (8)	0 (0)
Lusaka	67.4 (29)	75.0 (3)
Ndola	14.0(6)	25.0 (1)
Clinic		
Chiwempala clinic	18.6 (8)	0 (0)
George clinic	16.3 (7)	25.0 (1)
Kalingalinga clinic	16.3 (7)	25.0 (1)
Chawama clinic	14.0 (6)	25.0 (1)
Chipata first level	20.9 (9)	0 (0)
New masala clinic	20.9 (9)	25.0 (1)

(IDIs) with ALHA were conducted, each lasting for an hour, on average. Using both methods was appropriate given our study objectives: FGDs were conducted to understand commonalities and differences with ART treatment experiences among ALHA, and IDIs captured individual experiences, including sensitive and personal issues, further validating or providing nuances to FGD outputs. Zambian researchers were trained to ethically administer FGDs and IDIs, both of which were conducted in local languages. The researchers recorded, transcribed, and translated the interviews. The interview guides were developed by the research team in consultation with Save the Children. USAID was not involved in the interview-guide development.

Qualitative Data Analysis

Qualitative analysis was carried out using QRS NVivo version 10.0 using thematic analytic techniques. Two researchers read the transcripts independently to derive potential themes. Particular attention was paid to barriers and facilitators at the intrapersonal, interpersonal, institutional (i.e. facility), and community level during ART initiation, retention in care, and ART adherence stages of the CoC. We used the social ecological framework to guide the organization of qualitative findings [17]. This model has been widely used to guide studies of HIV prevention [19–21]. Researchers created a coding scheme to capture relevant themes and sub-themes within a multi-level framework. Researchers resolved coding discrepancies via deliberations. The thematic headings presented herein represent the outcome of the final stage of qualitative analysis.

Ethical Considerations

Ethical review and approval were obtained from the Boston University Institutional Review Board (IRB) and a Zambian IRB, ERES Converge. We obtained authority to conduct the study from the Zambia National Health Research Authority. All research activities adhered strictly to the Zambia National Health Research Act No. 2 of 2013, U.S. and international research ethics guidelines, including 45CFR46. All participants provided written informed consent. ALHA younger than 18 years provided assent and a parent provided consent.

Qualitative Results

Qualitative Participants

Older ALHA were interviewed for this study (17–19 years old). About 62.8% were males. Most of the participants were from Lusaka (67.4% of FGD participants, and 75% of IDI participants). Four IDIs were conducted with two male ALHA and two female ALHA.

Qualitative Data Findings and Themes

ALHA consistently reported similar barriers and facilitators in FGDs and IDIs. Therefore, the results from both methods are combined. For the qualitative data analysis, we focused on two stages related to retention: ART initiation and engagement in care (i.e. when a patient attends a clinic, meets national criteria for ART, and begins ART) and ART adherence and retention in care (i.e. uninterrupted ART coverage and routine HIV care) (Fig. 1). At both stages, we identified factors at the intrapersonal, interpersonal, institutional (i.e. facility), and community levels, presented in a continuum of care framework (Fig. 2). Cross-cutting factors (i.e. those that affect both stages) were also explored. Representative quotes from each of the listed key themes are summarized in *Electronic Supplementary Table I* (referred to as 'Supp. Table I' herein). The policy level is notably absent from the results, as adolescents did not explicitly report any policies (e.g. local, national) that affected ART initiation and engagement in care, or ART adherence and retention in care.

Art Initiation and Engagement in Care

ALHA reported intrapersonal level factors such as their low socioeconomic status, lack of adequate nutrition (which

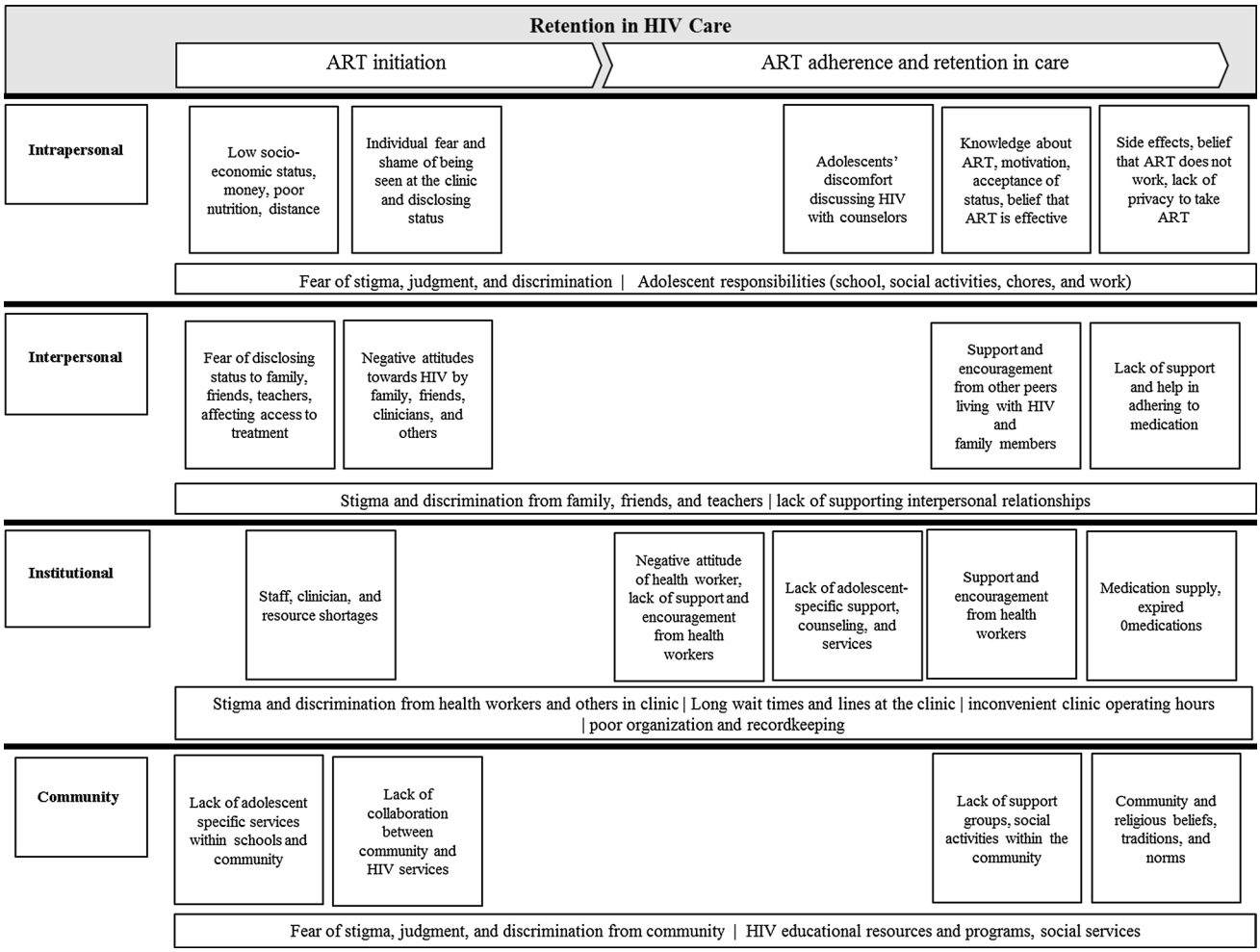

Fig. 2 Adolescent-identified* barriers and facilitators affecting retention in HIV care among adolescents living with HIV/AIDS. *adolescents did not identify polices as a barrier or facility to ART initiation, ART adherence, or retention in care. Therefore, the policy level was not included in the figure

could be considered a proxy for poverty), distance to clinic, and fear of being seen at an HIV clinic (Supp. Table I, quotes from FGDs: 1.1.1, 1.1.2, 1.2.1; quote from IDI: 1.2.2) as barriers to adherence to ART and retention in HIV care. ALHA also reported fear of disclosing their HIV status to others (family, friends, teachers, and clinicians) and negative attitudes about HIV of those individuals limiting their ability to seek treatment (including the initiation of ART). ALHA also stated that staff, clinician, and resources impeded their ability to access treatment (Supp. Table I, quote from FGD: 3.1.1). Within the community, several participants noted a lack of collaboration between HIV and community services as a barrier to obtaining access to ART (Supp. Table I, quote from FGD: 4.2.1: *"You find that at times people come and they want to get drugs but they do not know where to go and here they cannot find anyone to direct them."*) Other respondents also stated that the lack of adolescent-specific services affected their ability to get access to medication and information about the medication (Supp. Table I, quote from FGD: 4.1.1). ALHA did not identify any facilitators directly related to ART initiation.

ART Adherence and Retention in Care

Once an adolescent is connected to ART, there are numerous factors that affect their ability to be retained in care including to return for clinic appointments, obtain medication refills, and receive counseling by providers. On an intrapersonal level, ALHA did not feel comfortable discussing HIV with counselors and lacked adequate communication skills to discuss their concerns about ART, HIV, and HIV risk factors with adult clinicians (Supp. Table I, quote from FGD: 1.3.1). ALHA had issues with the medication, including burdensome side effects (Supp. Table I, quote from IDI: 1.4.2). Some respondents stated that they felt they no longer needed to take the medications once their health improved,

and therefore, stopped taking it (Supp. Table I, quote from FGD: 1.4.1). Numerous activities such as school, home duties, drinking, and social obligates interfered with retention in care and adherence to medications as shown in Supp. Table I, quote from IDI: 1.6.1; quotes from FGD: 1.6.2-1.6.3. However, ALHA did report facilitators to retention in care and ART adherence including support and encouragement from peers, family, and clinicians (Supp. Table I, quotes from FGDs: *2.6.1, 3,9.1;* quote from IDI: *2.6.2).* Additionally, participants stated that on an intrapersonal level, the knowledge about ART, acceptance of HIV status, and belief that ART is effective was an important facilitator to remaining in care (Table 3, quotes from IDIs: 1.7.1,1.8.2 *"I have the right information and it's the only thing I have to keep my life, if I stop I will die."*) ALHA also stated that on a community level, there are some HIV educational resources, programs, and social services that help ALHA adhere to medications and stay connected to HIV care (Supp. Table I, quote from IDI 4.6.1, quote from FGD: 4.6.2).

When asked which social and health services are currently available, ALHA listed the following: psychosocial support, household economic strengthening, birth registration, skills training, food/nutrition support, community HIV testing, health education, door-to-door testing, home visitation for adherence support, and voluntary male circumcision. Though the presence of such programs vary from community to community, resources specifically tailored for ALHA are often notably absent.

Cross-Cutting Themes

In addition to the themes presented above related to ART initiation and ART adherence separately, multiple cross-cutting themes (i.e. those that affect ART initiation, adherence to ART, and therefore, subsequent viral suppression) were identified. One such theme identified was fear of disclosure to family, friends, and clinicians (Supp. Table I, quotes from FGDs and IDIs: 1.2, 1.5, 2.1, 2.4, 3.5, 4.5), as exemplified by the following quote, 4.5.2 from a FGD: "*Sometimes your friends or your family can care for you, not other people. HIV is a big issue to disclose to other people in the community. If you tend to disclose, they will stigmatize you."* Other cross-cutting themes that were identified included facility level operations barriers, including long lines and wait times (Supp. Table I, quote from FGD: *3.6.1. "There are long queues waiting for long hours to get the services then you also have to wait for appointments. That is discouraging and it needs to improve.*), inconvenient clinic operating hours (Supp. Table I, quote from IDI: 3.7.1: "*They come here late to start working. You will find that we come here at around six, but they start showing up around eight to nine and then some of us we go to school and you don't want to miss school.")*, and poor organization and record keeping (Supp. Table I, quote from FGD 3.8.1: *"Every time I come here I find that my file is missing."*).

A factor, which is both a facilitator and a barrier, are community-based HIV resources. According to participants, there are many services including groups in schools, church, and the community (Supp. Table I, quote from IDI: 4.6.1; quote from FGD: 4.6.2) but few resources and services within health facilities are specifically for ALHA (Supp. Table I, quote from FGD: 3.3.1 *"I think there is need to come up with the day that will be specific for children and adolescents to come here at the clinic"* Supp. Table I, quote from FGD 3.3.2 *"I think they should bring in more health personnel so that others should be attending to the adults and others [to] the adolescents and children.").*

Quantitative Study of Factors Affecting Art Adherence and Retention in HIV Care

Quantitative Methods

Quantitative Sampling, Sources of Data, Data Collection Methods and Measurement

Quantitative study participants were sampled from Lusaka and Ndola. The study population included ALHA on the ART register at the University Teaching Hospital in Lusaka and the Arthur Davidson Children's Hospital in Ndola from April 1, 2014 through March 31, 2016. Of the estimated 5000 ALHA on the ART register, a random selection of 330 ALHA were included in our study. We anticipated that we would need a sample of 331 ALHA for this analysis based on our sample size calculations using the primary outcome of 14–36% loss to follow up (defined as not coming back for a scheduled review for a period of 3 months or longer from the last attendance or refill and/or review, and not yet classified as 'dead' or 'transferred-out') in Zambia. To determine the sample estimate, we estimated proportions with expected 36% loss to follow up, and a margin of error of $\pm 5\%$, and a 95% confidence interval.

ART adherence was measured using self-reported number of missed doses in the past week. Retention in care was measured with self-reported non-attendance of scheduled visits in the last 3 and 12 months.

Quantitative Data Analysis

We compared factors associated with ART adherence and retention in care between male and female ALHA by calculating prevalence ratios at 95% CI and with Chi square tests. An adjusted logistic regression model was also conducted to identify factors predictive of missing appointments, which included age, sex, school attendance, educational

level, marital status, socio-economic status, if a provider at a health institution (i.e. facility) recommended and initiated testing for HIV, employment status, and walking to HIV clinics to make scheduled appointments. Quantitative data was entered in CSPro v6.2. PSS (v16.0) and analyzed using SAS v9.4.

Quantitative Results

Quantitative participants

There were 330 18–19 year old ALHA in the quantitative portion of the study (Table 2). A total of 331 ALHA were approached for the study and all but one consented to participation in the study. However, the number of ALHA included in the analysis ranged between 256 and 330 as not all ALHA answered all survey questions. Of the ALHA who responded, 50.4% (n = 166/329) were currently attending school. The highest level of education completed was primary school for the majority of ALHA (72.5%, n = 235/324). Most participants were single/never married (97.9%, n = 323/330), and, of those who responded to the question on living arrangement most were living with parents (80.1%, 205/256). The majority of ALHA were students or unemployed (48.6%, n = 160/329, and 40.9%, n = 135/330 respectively), with only about 10.6% (n = 35/330) reporting current employment. About half of the adolescents (47.9%, n = 158/330) were on Atripla (efavirenz/emtricitabine/tenofovir) whereas lamivudine monotherapy (22.4%, n = 74/330) and tenofovir monotherapy (6.7%, n = 22/330) were less common. Nearly all participants reported disclosing their HIV status with someone other than a healthcare provider (96.7%, n = 319/330). Participants reported public bus as the most common mode of transport to the HIV clinic (51.7%, n = 169/327).

Quantitative Findings

Some ALHA reported experiencing difficulty with adherence to ART and retention in HIV care, as presented in Tables 3 and 4. A substantial portion of the population reported high levels of adherence, with about 81.8% (n = 180/220) reporting missing no doses in the past week. However, many reported ever forgetting to take medications (15.9%, n = 52/328), stopping medications because of side effects (5.3%, n = 11/209), or because they feel better (9.0%, n = 20/221). About 5.9% (n = 13/220) of ALHA reporting missing two to three doses of ART in the past week, and 1.8% (n = 4/221) reported missing more than three doses.

A large proportion of the study population had difficulty with retention in care; about 46% (n = 101/220) reported missing an ART clinic appointment in the past 3 months, with a higher proportion of female respondents missing appointments compared to male respondents (51.7%, n = 62/120, compared to 39.0%, n = 39/100, $p < 0.01$). There were no significant differences in any other measure of adherence or retention between males and females. ALHA reported that forgetting the appointment (45.5%, n = 15/33), lacking transport (24.2%, n = 8/33), and family commitments (15.2%, n = 5/33) were the most common reasons they missed appointments (Table 5).

Logistic regression modeling indicated the most common reasons for missing appointments were walking to the site of appointment (PR: 1.35, 95% CI 0.98, 1.84), which may be an indicator of time spent to travel to the clinic, and employment (PR: 1.51, 95% CI 1.04, 2.19). Provider initiated testing was predictive of not missing visits (PR: 0.61, 95% CI 0.43, 0.86) (Table 4). No other factors were significantly associated with missing appointments.

Discussion

We conducted a mixed-methods study to identify, understand, and describe barriers and facilitators and areas of improvement in ART initiation, adherence, and retention among ALHA. Understanding the barriers that discourage ALHA from engaging and retaining in care and from ART adherence.

In the qualitative portion of the study, ALHA identified multiple, significant, and compounding barriers affecting ART initiation, ART adherence, and retention in care such as stigma and discrimination (which contributed to psychological distress, and the fear of disclosing HIV status), poverty (as it related to nutrition and distance to health clinics), disrespectful treatment from clinicians, adolescent-specific responsibilities (e.g. school), and cultural beliefs and traditions about illness and western medicines. Facilitating factors included knowledge of ART efficacy, social support and counseling services; an adequate supply of ART medications was identified as a facilitator of ART adherence.

Our qualitative findings were corroborated by the quantitative results; a large proportion of ALHA reported difficulty with adherence and retention. The most common reasons for missing appointments were walking to the site of appointment and employment. Nearly all participants reported disclosing their HIV status to someone other than a healthcare provider, and yet, the fear of disclosure was discussed frequently in detail in all focus group discussions and in-depth interviews.

Our findings are consistent with some prior studies assessing factors affecting retention in HIV care among adolescents in non-Zambian context [22–31]. However, many of these factors have been not consistently associated with poor adherence to ART or retention in care, indicating there is a gap in understanding barriers and facilitators contributing

Table 2 Demographic characteristics of adolescents living with HIV/AIDS in Zambia (N = 330)

Characteristic	All Participants	Male	Female
Number of subjects	330	158	172
Education			
Ever attended school	97.9% (323/330)	96.2% (152/158)	99.4% (171/172)
Currently attending school	50.4% (166/329)	55.1% (87/158)	46.2% (79/171)
Highest level completed			
Never attended	17.6% (57/324)	21.1% (32/152)	14.5% (25/172)
Primary	72.5% (235/324)	73.7% (112/152)	71.5% (123/172)
Secondary	9.6% (31/324)	5.3% (8/152)	13.4% (23/172)
Marital status			
Single/never married	97.9% (323/330)	98.7% (156/158)	97.1% (167/172)
Widowed	0.6% (2/330)	0.6% (1/158)	0.6% (1/172)
Married	1.5% (5/330)	0.6% (1/158)	2.3% (4/172)
Separated	0.0% (0/330)	0.0% (0/158)	0.0% (0/172)
Divorced	0.0% (0/330)	0.0% (0/158)	0.0% (0/172)
Living arrangement			
Lives with parents	80.1% (205/256)	80.6% (100/124)	79.5% (105/132)
Lives with spouse and children	2.0% (5/256)	0.8% (1/124)	3.0% (4/132)
Lives in a family household	11.3% (29/256)	8.9% (11/124)	13.6% (18/132)
Lives with one or more friends	5.1% (13/256)	6.5% (8/124)	3.8% (5/132)
Number of people in household			
1–5	45.8% (151/330)	48.7% (77/158)	43.0% (74/172)
6–10	51.2% (169/330)	48.7% (77/158)	53.5% (92/172)
More than 10	2.1% (7/330)	1.3% (2/158)	2.9% (5/172)
Number of different places lived in past 12 months			
1	56.0% (183/327)	59.4% (92/155)	52.9% (91/172)
2	30.0% (98/327)	27.7% (43/155)	32.0% (55/172)
3	11.3% (37/327)	9.7% (15/155)	12.8% (22/172)
4	2.8% (9/327)	3.2% (5/155)	2.3% (4/172)
Number of months in past year had a job			
1–4	5.2% (17/330)	6.3% (10/158)	4.1% (7/172)
5–8	3.0% (10/330)	1.3% (2/158)	4.7% (8/172)
9–12	1.5% (5/330)	1.9% (3/158)	1.2% (2/172)
Main occupation			
Unemployed	40.9% (135/330)	38.0% (60/158)	43.6% (75/172)
Student/pupil	48.6% (160/329)	54.1% (85/157)	43.6% (75/172)
Currently working	10.6% (35/330)	8.2% (13/158)	12.8% (22/172)
Disclosure			
Anyone other than health care provider know HIV status	96.7% (319/330)	95.6% (151/158)	97.7% (168/172)
Antiretroviral therapy regimen			
Atripla (efavirenz/emtricitabine/tenofovir)	47.9% (158/330)	46.2% (73/158)	49.4% (85/172)
Lamivudine monotherapy	22.4% (74/330)	27.8% (44/158)	17.4% (30/172)
Tenofovir monotherapy	6.7%(22/330)	6.3% (10/158)	7.0% (12/172)
Mode of transport to the clinic			
Walking	28.7% (94/327)	23.6% (37/157)	33.5% (57/170)
Bicycle	4.3% (14/327)	6.4% (10/157)	2.4% (4/170)
Car	13.1% (43/327)	10.8% (17/157)	15.3% (26/170)
Motorbike	0.3% (1/327)	0.0% (0/157)	0.6% (1/170)
Taxi	1.8% (6/327)	1.9% (3/157)	1.8% (3/170)
Public bus	51.7% (169/327)	57.3% (90/157)	46.5% (79/170)

Table 3 ART adherence among adolescents living with HIV/AIDS in Zambia (N = 330)

Variable	All participants	Male	Female	Prevalence ratio (95% CI)
Number of subjects	330	158	172	
ART adherence	All participants	Male	Female	Prevalence ratio (95% CI)
Ever forget to take ART medications	15.9% (52/328)	16.7% (26/156)	15.1% (26/172)	1.10 (0.67–1.82)
Stop taking ART because of side effects	5.3% (11/209)	5.2% (5/96)	5.3% (6/113)	0.98 (0.31–3.11)
Stop taking ART because feel better	9.0% (20/221)	7.0% (7/100)	10.7% (13/121)	0.65 (0.27–1.57)

Number of times missed ART dose in last week	All participants	Male	Female	Chi square statistic	*p* value
None	81.8% (180/220)	81.0% (81/100)	82.5% (99/120)	0.0245	0.99
Once	12.7% (28/220)	13.0% (13/100)	12.5% (15/120)		
Two to three times	5.9% (13/220)	6.0% (6/100)	5.8% (7/120)		
More than three times	1.8% (4/220)	1.0% (1/100)	2.5 (3/120)		

Number of times took ART hour too soon or too late in last week	All participants	Male	Female	Chi square statistic	p-value
None	71.0% (157/221)	68.0% (68/100)	73.6% (89/121)	2.4466	0.49
Once	16.3% (36/221)	16.0% (16/100)	16.5% (20/121)		
Two to three times	10.9% (24/221)	13.0% (13/100)	9.1% (11/121)		
Four or more times	1.8% (4/221)	3.0% (3/100)	0.8% (1/121)		

to losses among ALHA in Zambia and elsewhere. [11, 14, 16] In a recent study of ALHA in the Copperbelt region of Zambia found that factors significantly associated with a 48-h ART gap were being male, not everyone at home being aware of their HIV status, and alcohol use in the last month [31]. Mutumba et al. found that increased social psychological distress was significantly associated with increased odds of missing pills in past 3 days (OR: 1.75; CI 1.04–2.95), lower self-rated adherence (OR: 1.79; CI 1.19–2.69), and not following the prescribed regimen (OR: 1.63; CI 1.08–2.46) [22]. Additionally, psychosocial resources were associated with lower odds for non-adherence on all measures [22]. This finding was consistent with our qualitative findings, in which ALHA expressed psychological distress as a result of their HIV status, and fear of disclosing their HIV status affecting their ability to both initiate ART and stay on treatment.

Our finding that fear of reactions to a HIV status significantly impacted an adolescent's ability to disclose their HIV status, seek treatment, and retain in care is a recurrent theme in most prior studies on ART adherence and retention [23, 24]. Prior studies have found that ALHA in Zambia who had not disclosed their HIV status are significantly less likely to be receiving ART treatment, as complete disclosure and strong parental relationships are related to good adherence [23–25].

Further, our finding that poverty is a barrier to ART initiation, retention and adherence is also consistent with findings from similar studies from non-Zambian contexts. That is, prior studies have consistently found that poverty is related to worse HIV care retention, and subsequently, adverse health outcomes [24]. A study on ALHA in Ethiopia noted that cost and access to transportation, economic problems in the household, and lack of adequate nutrition impacted the ability to adhere to ART [25]. The problems of access to nutrition are largely ignored in most prior studies, though a few that have explored this issue have found that food insecurity is common in resource-poor settings, and contributes to worse-health related outcomes including increased hospitalization, higher morbidity, decreased quality of life, and depression among people living with HIV [26]. A study conducted in Niger indicated that family nutritional support improved survival, immune restoration, and adherence among HIV patients on ART [28]. Lastly, ALHA raised belief systems as another barrier. Multiple participants expressed distrust in the medications, including not believing that they worked, or receiving advice from pastors, religious leaders, and community members to pray for the disease to go away. These traditional beliefs may be grounded in local concepts of illness, and a distrust of Western medicine [29, 30].

Our findings generated important insights about HIV intervention design. Because ALHA reported numerous barriers to adherence at all levels, multi-level approaches to HIV services could be effective in reducing the key issues around retention and adherence among ALHA in Zambia. A single intervention aimed at only one single barrier is insufficient to address the multiple compounding issues faced by

Table 4 Retention in HIV care among adolescents living with HIV/AIDS in Zambia (N = 330)

Variable	All participants	Male	Female	Prevalence ratio (95% CI)	p-value
Number of participants	330		158		172
ART care retention[a]	All participants	Male	Female	Prevalence ratio (95% CI)	p-value
Missed clinic appointment during previous 3 months	45.9% (101/220)	39.0% (39/100)	51.7% (62/120)	0.63 (0.47–0.84)	0.01
	All participants	Male	Female	Chi square statistic	p-value
Number of times missed clinic appointments in last 6 months[a]					
None	84.1% (249/296)	85.6% (119/139)	82.8% (130)	0.3805	0.94
Once	12.5% (37/296)	12.9% (18/139)	12.1% (19)		
Two	1.7% (5/296)	1.4% (2/139)	1.9% (3)		
Three or more times	0.7% (2/296)	0.0% (0/139)	1.3% (2)		
Number of times missed clinic appointments in last 12 months[a]					
None	87.6% (261/298)	89.3% (125/140)	86.1% (136)	1.465	0.69
Once	8.1% (24/298)	6.4% (9/140)	9.5% (15)		
Two	0.7% (2/298)	1.4% (2/140)	0.0% (0)		
Three or more times	2.3% (7)	2.1% (3/140)	2.5% (4)		
	All participants	Male	Female	Prevalence ratio (95% CI)	p-value
Reasons for missing any of the clinic appointments					
Lack of transport	24.2% (8/33)	15.4% (2/13)	30.0% (6/20)	0.51 (0.12–2.16)	0.35
Forgot the appointment	45.5% (15/33)	53.8% (7/13)	40.0% (8/20)	1.35 (0.65–2.81)	0.44
Family commitments	15.2% (5/33)	23.1% (3/13)	10.0% (2/20)	2.31 (0.44–11.98)	0.31
Work commitments	6.1% (2/33)	7.7% (1/13)	5.0% (1/20)	1.54 (011–22.49)	0.76
Attended another clinic	6.1% (2/33)	0.0% (0/13)	10.0% (2/20)	N/A[b]	0.25
Not happy with quality of care at clinic	3.0% (1/33)	0.0% (0/13)	5.0% (1/20)	N/A[b]	0.42
Suggested interventions most likely to help adolescent not to miss clinic appointments in future					
To be visited at home	18.4% (7/38)	12.5% (2)	22.7% (5)	0.55 (0.12–2.49)	0.43
To be sent text message reminders over the phone	65.8% (25/38)	81.3% (13)	54.5% (12)	1.49 (0.95–2.33)	0.09
Improved quality of care at clinic	15.8% (6/38)	6.3% (1)	22.7% (5)	0.28 (0.04–2.13)	0.18

[a]There were some inconsistencies with reporting missed appointments; 80 subjects who said that they had missed an appointment in the past 3 months had missed no appointments in the past 6 months and 88 stated that they who had missed no appointments in the past 12 months

[b]There were no males who attended another clinic or who were not happy with quality of care, and therefore, the prevalence ratio cannot be calculated

Table 5 Adjusted[a] logistic results of factors associated with missed appointments among adolescents living with HIV/AIDS in Zambia

Predictor	Prevalence ratio (95% CI)
Walking to appointments	1.35 (0.98, 1.84)
Provider initiated testing[b]	0.61 (0.43, 0.86)
Currently employed	1.51 (1.04, 2.19)

[a]Adjusted for the following covariates: age, gender, school attendance, educational level, marital status, socio-economic status, and distance from health facility

[b]This refers to if a provider at a healthcare facility recommended and initiated testing for HIV

ALHA. Many of the issues raised by ALHA were attributed to multiple, cross-cutting issues such as perceived stigma and discrimination from clinicians and community members [29, 30, 32–34].

Fortunately, there are multiple effective approaches to combating stigma, discrimination and lack of knowledge, including information-based approaches, which aim to increase knowledge through written materials, skill building approaches which aim to resolve negative attitudes, counseling strategies, and contact and interactions with people living with HIV and the general public [29]. Many of these approaches have demonstrated effectiveness and should be considered for this population of ALHA in the Zambian context [35–45].

The strengths of this study include its mixed-methods approach. The qualitative portion of the study provide unique insight into the experiences of ALHA as they engage in treatment, initiate ART, and adhere to treatment.

Qualitative and quantitative methods triangulated the findings and provided a more comprehensive understanding of the factors that affect adherence to ART and retention in care than one method could do alone. Despite the aforementioned strengths, the study has limitations. The study participants that took part in focus group discussions and in-depth interviews were predominately from Lusaka, which is urban and has largely accessible HIV clinics. Therefore, the experiences of ALHA living in remote areas of Zambia may not have been captured as extensively in this work. Similarly, participants in the quantitative arm of the study were only recruited from Lusaka and Ndola, which could limit the generalizability of the findings. Additionally, ALHA were approached for qualitative data collection based on consultations with stakeholders from health and social welfare systems. These ALHA were likely more stable and well-connected to care, compared to other ALHA around the country. We collected background information on ALHA participating in FGDs and IDIs but did not collect information on their age of ART initiation or ART tenure, as we did not anticipate our findings to change in any meaningful way depending on this variation. Similarly, we did not systematically collect facility-level data on available support services (i.e. HIV support groups, youth friendly corners). However, we did ask qualitative participants about available services and recruited different types of health facilities (e.g. University Teaching Hospital which is a center for excellence for adolescent and children's health, and small community health facilities).

In spite of these limitations, we believe that our work describing barriers and facilitators to HIV care among ALHA in Zambia is important to consider when developing interventions. Future research should focus on ALHA in rural areas and those not connected to HIV care. Programs that focus on addressing barriers on multiple levels of the socio-ecology may be effective in improving ART adherence and retention in HIV care.

Conclusion

This mixed-methods study describes a multi-level framework for understanding factors that affect ART initiation, ART adherence, and retention in care among ALHA in Zambia. Our quantitative and qualitative findings highlight the interrelated and complex issues that ALHA face when seeking and remaining in HIV care. Interventions that may improve adherence to ART and retention to HIV services to move Zambia towards attainment of the UNAIDS 90–90–90 targets are those that can be implemented to address multiple barriers at multiple levels of the social ecology.

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