

Facilitators and Barriers of Self-Disclosure of HIV Status Among Adolescents Aged 10-19 Years in Makerere University Joint AIDS Program: A Qualitative Study

Dorothy Gingo^{3*}, Robert Opika Opoka¹, Oliver Ombeva Malande^{1,2,4,5}, Joseph Rujumba¹ and Sabrina Bakeera Kitaka¹

¹Makerere University College of Health Sciences, Paediatrics department, Kampala-Uganda

²East Africa Centre for Vaccines and Immunization (ECAVI), Kenya- East Africa

³Infectious Diseases Institute, Makerere University, Kampala-Uganda

⁴Moi University, Department of Paediatrics and Child Health, Eldoret, Kenya

⁵Department of Public Health Pharmacy, Sefako Makgatho Health Sciences University, Pretoria, South Africa

***Corresponding Author:** Dorothy Gingo, Infectious Diseases Institute, Makerere University, Kampala-Uganda, E-mail: igingd@gmail.com

Received Date: May 24, 2024 **Accepted Date:** June 24, 2024 **Published Date:** June 27, 2024

Citation: Dorothy Gingo, Robert Opika Opoka, Oliver Ombeva Malande, Joseph Rujumba, Sabrina Bakeera Kitaka (2024) Facilitators and Barriers of Self-Disclosure of HIV Status Among Adolescents Aged 10-19 Years in Makerere University Joint AIDS Program: A Qualitative Study. J HIV AIDS Infect Dis 11: 1-16

Abstract

Introduction: In Uganda, 1.4 million people are living with HIV with a prevalence 5.5% among 15-49 year olds. Despite efforts and regulation for mandatory disclosure, non-disclosure of HIV sero-status to others remains high, which contributes to the high rates of new infections, poor adherence to treatment and low retention in care. We aimed to explore the facilitators, barriers, and consequences of self-disclosure among adolescents attending Makerere University Joint AIDS Program (MJAP).

Methodology: This qualitative study was conducted at Makerere University Joint AIDS Program among ALHIV 10-19 years who knew their HIV status and 7 health care workers that had worked at the adolescents' clinic for at least 3 months. Twenty adolescent In-depth interviews and 7 Key Informant interviews were conducted using interviewer administered interview guides. Data was analyzed using content thematic analysis.

Results: The average age of the adolescents was 16 years (IQR 12-18). Facilitators to self-disclosure included need for support, knowledge about HIV, built trust, continued counselling and peer-to-peer interactions. Barriers to self-disclosure in-

cluded stigma, lack of knowledge of how to start, parental influence, and desire for HIV negative partner, others found no need to disclose. Among those who disclosed, positive consequences included; support, viral suppression, happiness and sensitization of others. Negative consequences included; domestic violence, rejection by friends and/or relatives, job loss, and depression among others.

Conclusion: The rate of self-disclosure in this study was relatively low, with stigma as a major barrier and need for support as a major facilitator.

Recommendation: There is a need for key stakeholders to develop strategies to overcome the barriers and improve self-disclosure among adolescents so as to increase ART adherence, retention in care and reduction of HIV transmission.

Keywords: HIV; AIDS; New Infections; ART Adherence; HIV Transmission

Introduction

By the end of 2022 there were about 39 million people living with HIV globally, 6.7% of these were Children and adolescents 0-19 years and about 20% of new adult HIV infections [1]. In Uganda, 1.4 million people were living with HIV in December 2021, with prevalence 5.5% among 15- 49 year old age group[1,2].

Worldwide, societal shifts and behavioral patterns exacerbated by unique developmental vulnerabilities create a confluence of factors that place today's adolescents at heightened risks for poor health outcomes [3].

Self-disclosure aims “to let another person know with no shadow of a doubt what you have done, what you feel, etc.” There are two types of disclosure; Personal self-disclosure and relational self-disclosure [4].

Studies have indicated six benefits of self-disclosure; emotion expression, self-clarification, social-validation, relationship development, social control, and intimacy accommodation. Ando later divided the six benefits into two categories: Personal benefit (emotion expression, self-clarification, and social-validation) and interpersonal benefit (relationship development, social control, and intimacy accommodation) [5]. Positive sides of self-disclosure; in human relationships, the reciprocity nature enhances social intimacy in terms of creating relatedness, liking, and respect among people [5,6]. Self-disclosure is also beneficial in interpersonal relationship in a way that it creates close relationship and maintains an individual's psychological well-being [7].

Although self-disclosure is a catalyst in bringing people closer together, it can inflict tension resulting into social isolation as well. Some studies, on disclosure of HIV status to one's sexual partner, found both positive and negative consequences. Negative consequences included rejection, stigma, loss of intimacy, and threats to personal well-being [7,8]. A Meta-analysis review documenting 3 distinct but overlapping mechanisms that account for the link between self-disclosure and relationship closeness revealed that people disclose more to someone whom they like. People like someone more who discloses to them, and to whom they have disclosed personal information [9].

Both globally and within the sub-Saharan African region, a spate of recent laws, policies and programs have tried to encourage or in some cases mandate HIV disclosure. For example, the World Health Organization (WHO) in 2011 published guidelines on HIV disclosure counseling for children up to 12 years of age. Also the Uganda HIV Prevention and Control Act, of 2014 legislates for mandatory testing of HIV, mandatory disclosure of a person's HIV status and the criminalization of intentional spread of the HIV [10]. It also criminalizes HIV transmission, attempted transmission, and behavior that might result into transmission by those who know their HIV status [10]. These policies have generated ethical and policy debates. Despite initiatives to encourage voluntary HIV disclosure and to increase partner testing in sub-Saharan Africa, health workers continue to grapple with difficult challenges in the face of failure to self-disclose.

A large body of research indicates that gender is-

sues are key to HIV disclosure in Africa [11]. Other challenges to self-disclosure include low self-efficacy, low self-esteem, education status-not being in school, low social economic status, fear of discrimination and age where the older adolescents are more autonomous thus strive to keep their HIV status as a secret until when they find the right time, place and person to disclose to.

Taken as a whole, this evidence suggests a need for more attention to the challenges and dilemmas faced by both clients and providers in relation to HIV disclosure in this region and for continued efforts to consider the perspectives and rights of all those affected [12,13]. This study was aimed at answering the question of what facilitates or challenges adolescents to disclose their HIV status.

Materials and Methods

Study Design

A qualitative cross sectional study was conducted.

Study Setting

Study Site: Makerere University Joint AIDS Program (MJAP), Kampala *also known as* Mulago ISS Clinic is an HIV clinic located on Mulago hill and is a Centre of Excellence for comprehensive HIV services. The clinic is funded by CDC/PEPFAR through Infectious Diseases Institute (IDI) under Mulago National Referral Hospital, run by Makerere University Joint AIDS Program (MJAP), and was opened in 2004, as an expansion of Mulago HIV clinic. It is an outpatient clinic but links critical patients to Mulago Hospital for inpatient services also in Kiruddu hospital which is supported by MJAP. Currently, the clinic offers comprehensive HIV/AIDS services to over 15,000 patients (children, adolescents, young adults and adults), of which over 95% are on ART. The clinic has over 280 adolescents, all of whom are on ART. There are specific consultation rooms/counseling rooms for children and adolescents, at Annex (Room 3, 4 and 5). On Wednesday, the clinic receives 30-40 adolescents, and about 10 adolescents on other week days except public holidays and weekends. There are 4 Medical Officers, 3 clinical officers, 4 general counselors and 4 PATA-trained peer counsellors (3 females and 1 male) who conduct individual and group counselling daily

where the adolescents are encouraged to disclose, or assisted disclosure may be employed when the adolescent accepts.

Selection Criteria: Adolescents aged 10-19 years at MJAP clinic, who knew their HIV status and the health care workers that had worked with Adolescents for at least 3 months.

We included all adolescents aged 10-19 years that attended MJAP Clinic-Kampala who knew their HIV status, had been on ART for at least 6 months and gave informed consent or assent.

We excluded those adolescents who were unable to communicate during participation in the study.

Sample Size Estimation

We purposed to conduct interviews until no new ideas (saturation) emerged.

Sampling Procedure: The selection of study subjects was done by purposive sampling. The adolescents, who had to be peer leaders or support group heads, or selected by the research assistants based on their disclosure status were interviewed by the P.I. In the selection we considered that; Self disclosure is the ability to reveal personal, intimate information about their HIV status that has previously been a secret. Possible consequences of self-disclosure of HIV status at individual, peer, family, or community level; both positive and negative outcomes.

Quality Control

All research assistants were trained for two days to ensure capacity and knowledge on the data collection tools, interviewing techniques and note taking. They partly participated in the building of the study tools, which were pre-tested with them. A social scientist with experience in qualitative research was part of the coding team.

Data Collection Procedures

We conducted in-depth interviews and Key Informant Interviews. For the interviews, KIIs were among focal persons at MJAP, then IDIs were equally distributed among

adolescents who had disclosed and those who had not disclosed, until no new ideas emerged (saturation).

In-depth interviews: Twenty in-depth interviews were conducted with adolescent peer leaders, support group heads and adolescents who were willing to share their experiences about what facilitated them to or barred them from disclosing their HIV status to other people. IDIs were equally distributed among the adolescents who had disclosed and those who had not disclosed, half the participants were males. We had 16 of these adolescents in school, most in secondary school while the rest were in primary school. The 4 remaining adolescents were employed (1- a hair dresser, 1- a house help, 2 of the males were casual labourers) with salaries ranging from 50,000- 200,000 shillings per month. The P.I concluded at 20 IDIs when no new ideas emerged (saturation). Issues explored during interviews included; adolescent's testing experience, disclosure to others and impact of disclosure, who they disclosed to and why and fears about disclosure and, factors that would aid future self-disclosure. The interviews were conducted by P.I, in the participant's preferred language-mostly Luganda, audio recorded, and notes taken. The MJAP training room was used for the interviews which last a duration ranging from 18-45 minutes.

Key Informant Interviews: These were conducted with 7 purposively selected health workers who had worked with adolescents for at least 3 months in MJAP clinic. These included 2 peer educators, 1 counsellor, 4 Adolescent focal persons (3Doctors and 1Nurse). The semi-structured interview guide consisted of structured questions on, category/-position of respondent, length of time the health worker had been involved in activities and services related to Adolescent HIV care, which was followed by open ended questions on health workers' perspectives with regards to facilitators and barriers to self-disclosure among ALHIV. The PI conducted the interviews in the MJAP training room, together with a social scientist and/or one of the research assistants who took notes and audio recorded the sessions. These KIIs which last 15 to 30 minutes, enabled us to explore how the health services met the adolescent needs and how adolescent self-disclosure practices could be supported and improved at MJAP and other HIV care centers.

Data Management and Analysis

All tools for data collection, like CD drives, were kept in a secure place under lock and key by the principle investigator.

Analysis of the qualitative data was manually done at the end of each day for the first week, then end of each week during the data collection period. Preliminary analysis of some scripts, done manually, at end of each day enabled us to identify issues to probe on in subsequent interviews regarding self-disclosure.

The data was transcribed, translated by the team collecting data (comprising of the principal investigator, the social scientist and research assistants), and coded appropriately. The Luganda audio-records were translated to English by the P.I who is fluent in Luganda and English.

Content thematic approach was used to analyse the data. This involved use of codes in the interview guide which were refined through reading the interview scripts. The code book was updated alongside the periodic analysis, with continuous theme search and review of transcripts by the corresponding author in consultation with the other authors to agree on the final codebook. The corresponding author coded all the transcripts and held periodic debrief meetings with the study team to discuss emerging study findings.

Data were then grouped in themes and sub-themes with corresponding illustrative voices. We also compared findings within and across age and self-disclosure status groups.

Ethical Consideration

Ethical approval was sought from Makerere University College of Health Sciences- Research and Ethics committee, acceptance for study site was obtained from the Research committee at MJAP-ISS clinic.

We obtained written informed consent and Assent from all the children/ empowered minors enrolled into the study. Parental consent was also obtained for some adolescents enrolled. Briefing about the study was done by peer counsellors and enrolment done by the P.I.

Confidentiality was kept by study team, all filled questionnaires or transcripts were kept under lock and key by the P.I

There was a regular Psychiatrist at MJAP who assisted with mental Health Assessment and management of any adolescents who needed help after the interview. She also assisted with assessment of cognitive function for some participants who took part in In-depth interviews.

Results

Adolescents who had already been attending care at MJAP were enrolled into the study between April and June 2019, where they came on their appointment date got briefed about the study.

Demographic Characteristics for the Adolescents Enrolled for the Study

The mean age of the adolescents was 15.5 ± 2.9 years, maximum was 19, and minimum was 10years. And the median age was 16years IQR (12-18).

Table 1: Thematic presentation of facilitators and barriers of self-disclosure of HIV status among adolescents attending MJAP clinic

Theme	Sub-theme	Codes	
Facilitators	Individual factors	Need for support Empowerment from clinic Information about HIV built trust	Gender Older age Clinical condition Prevent transmission
	Health facility factors	Continuous counselling Peer to peer interactions Assisted partner notification(APN)	
	Societal factors	Counselling Peer influence Sensitized friends Death of parent(s)	
Barriers	Individual factors	Stigma Limited Information about HIV Being in denial	Fear of the unknown Desire for HIV negative partner Don't know steps
	Health facility factors	Long queues Negative attitude of health workers Some don't talk about benefits of disclosure Irregular peer support meetings	
	Societal factors	Parents refusal Violent partner Stigma Prejudice	
Consequences	Positive effects	Social support, Partner testing, Built self-esteem, Good adherence, Good relationships	
	Negative effects	Domestic violence, Stigma/rejection, Low self-esteem,	Loss of jobs Change of school Psychiatric effects

Qualitative Results

Participants for this data were adolescents who

were peer leaders and willing to take part in the in-depth interview or health workers who were focal people for adolescent care and/or had spent at least 3 months in the MJAP

clinic. These alluded to multiple factors and outcomes which are summarized in the table above.

Facilitators of Disclosure

The major facilitators to self-disclosure were broadly grouped under individual like need for support from others, built trust over time and knowledge about HIV. Then health facility factors like continuous counseling at clinic, peer-to-peer interactions and then societal factors like sensitized friends, and death of parent(s).

Individual Factors

Knowledge About HIV

In-depth and key informant interviews revealed that when adolescents are told what exactly HIV is, they find it possible to disclose to others.

“I got some information about HIV from health talks at the clinic and internet, which I shared with my best friend. When I sensitized my friend about HIV, a time came when I knew that he was knowledgeable about it, how it is and what to do about it, then I was able to tell him.” [IDI 20, 19 yr male].

Need for Support. Most adolescents and key informants noted that the need for support enabled adolescents to disclose their HIV status to family members and friends as some explained:

“I had to tell my family members because I needed support, and a place to run to in case I have any problem.” [IDI 12, 19yr female]

A health worker added:

“They disclose to get support from those they are living with” [KII 03, Intensive adherence counsellor]

Source of HIV Transmission. Some key informants reported an observed difference in the disclosure patterns among adolescents who had acquired the HIV infection vertically from those who had acquired it during adolescence. For example:

“Those who acquired it during adolescence tend to

be more positive about care, they own their decisions and what you tell them, unlike those who were born with HIV who push it back to you; it is your thing...” [KII 04, Doctor]-
That is contrary to what KII 02 reported that “those who got it from their mothers find it easier to disclose, since they say it wasn’t their fault.”

Clinical Condition of the Adolescent

One adolescent shared that when she developed signs of HIV, (as she was told in the clinic where she went) she had to tell the caretaker. .

“I got a painful rash which they told me was kisipi (herpes zoster), then they told me I had to go to Mulago. I didn’t have transport so I had to tell my paternal aunt what I was told at clinic” [IDI 02, 16yr female]

Key informants noted that adolescents who are weak or sickly tend to disclose their HIV status to others compared to those looking healthy.

“When the patients are very sick, they easily share their status with their caretakers” [KII 03, Adult/intensive adherence counsellor]

Trust Built Over Time

Most of the adolescents and key informants reported that the adolescents disclosed once they built trust with whoever they related with, and that took varying durations. As some explained, *“Once someone has taken their time with another, they study the person to know their personality before disclosing to them”* [IDI 20, 19yr male]

“After some time, like when I know she is serious, I would first try to talk about it like I mean someone else, I get her reaction, which makes me know if I can disclose” [IDI 14, 15yr male]

In relation to adolescents’ first building trust, a doctor commented *“They want to take some time to develop trust for whoever they plan to disclose to ...there should be some steps one takes to assess someone before you tell them your secret”* [KII 05, Doctor]

Health Facility Factors

Continuous Counselling About Self-Disclosure

Adolescents mentioned that continuous counseling by health care workers had facilitated them to disclose their HIV status to others some explained:

“We are usually advised at the clinic to disclose to a trustable person, to get support” [IDI 01, 14yr female].

The role of continuous counseling as a facilitator of self-status disclosure was also highlighted by key informants as one noted:

“...if they (adolescents) hear the same message from their clinicians/counsellors, they (adolescents) get knowledge about how to disclose, thus end up disclosing.” [KII 06, male peer educator]

Some of the counseling messages emphasized the need to prevent HIV transmission to others which encouraged disclosure.

“...you may have many girlfriends, and it won't be fair to transmit the virus to them” [IDI 16, 19yr male]

Another adolescent added, *“...I have to tell my partner or anyone I live with because I don't want to infect them. Then they decide whether to stay with me or not” [IDI 09, 19yr female]*

Some key informants noted that adolescents often encourage partners to attend the clinic with them so that they get assistance from health care providers regarding disclosure as one KII explained:

“We want HIV to stop with them (adolescents) because if they don't disclose, they are going to spread it, but when they disclose they bring the partner to the clinic and we test them. If the partner is negative, we connect them for preventive services” [KII 06, male peer educator]

Peer to peer interactions through weekend activities at clinic. *“Usually when you involve their peers that helps them to come around, accept the diagnosis and open up to others. We also assist some to disclose to their partners, Assisted Partner Notification/APN” [KII 04, Doctor]*

Assisted partner notification (APN) was report-

ed by some key informants as one of the strategies used at MJAP clinic to facilitate self-disclosure. It was also requested by some adolescents.

“...some adolescents fail to disclose on their own, but we ask them to bring their partners to the clinic and we assist them to disclose, then do couple counselling.” [KII 06, male peer educator]

Barriers of Self-Disclosure of HIV Status Among Adolescents

The main barriers to self-disclosure of HIV status among adolescents were also described broadly under individual, health facility and societal factors. They included; stigma, being in denial, parental discouragement, a common desire for a negative partner and fear for the unknown.

Individual factors

Fear of Stigma or Rejection

This was a major finding from the in-depth interviews and the key informant interviews.

“I have not told anyone because they may abuse/torment you and tell others who may point fingers at you” [IDI 19, 15yr female].

Another adolescent said, *“...I don't want to tell my friends or teachers because they may spread the news in the whole school and people gossip about you” [IDI 18, 17yr female]*

“Other people have self-stigma where they get discriminated by others and they feel they are not worthy” [IDI 20, 19yr male].

Adolescents' fear of rejection by the sexual partners was also mentioned by key informants.

“They fear to be rejected. They tell you that I will not disclose to this boyfriend because he will leave me, yet they dream of a future where they want to get married and get children” [KII 01, nurse]

Another health worker reported that one adolescent told him that,

“Musawo (doctor), I can’t do it (disclose) again because I lost the other partner, I don’t want to lose another or be discriminated” [KII 06, male peer educator]

Living in Denial, thus Unable to Disclose

Some adolescents are told their HIV results but may not believe or accept them readily. This may be because they have no obvious signs of HIV/AIDS or they are undergoing the psychological process after receiving bad news slowly. For example, this adolescent said,

“I was tested but didn’t believe since my sister didn’t have the virus...” [IDI 16, 19yr male]

A clinician added that, *“some have not accepted that they are HIV positive” [KII 01, Nurse]*

Having multiple sexual partners was reported as a barrier to self-disclosure among some adolescents attending MJAP clinic. For example,

“You know at this age you can have many girlfriends, but truly you may just be there not meaning it yet she is serious, so you can’t tell all of them...” [IDI 16, 19yr male]

Another adolescent reported *“I also have another one who is interested in me and keeps telling me to go test but I get excuses. I told another one to go to hospital but he doesn’t want so I don’t know their status” [IDI 12, 19yr female]*

Limited Information about HIV and how to Disclose

Some participants mentioned having limited information about HIV as a barrier to self-disclosure. *“Some people have wrong biology about HIV. So they think they don’t have to tell relatives since they will die anyway” [IDI 16, 19yr old male]*

One of the key informants also reported that, *“Some people lack information about HIV; they still have a mentality that when they have HIV they are going to die or they are useless. Since they lack information, it makes it hard to disclose” [KII 06, male peer educator]*

It was also noted that some adolescents lack infor-

mation on how to start disclosure.

“I think I will not disclose because I don’t have a starting point for telling another person” [IDI 19, 15yr female]

Related to that barrier of lack of a disclosure process, one of the key informants reported,

“These adolescents don’t know how to start. I attended a clinic where mothers were being taken through a step by step way of disclosing to their children; if even parents find it so hard to disclose to their children and end up telling them they have pneumonia...” [KII 05, Doctor]

Desire for an HIV negative partner. Some adolescents hesitated to disclose their HIV status because they want HIV negative partners and they assumed that disclosure would hinder them from fulfilling this desire, as some explained:

“Honestly, this age of ours makes you want to have a girlfriend and for me I just don’t want a girl of my status, but in my thinking she may run away when she learns my status” [IDI 16, 19yr male] And another adolescent added,

“The other casual partner is negative and has no problem relating with me, but needs/is trying to know how we can survive together in this status” [IDI 09, 19yr female].

The views of adolescents regarding the common desire for an HIV negative partner were also confirmed by key informants as one noted:

“Positive adolescents want negative partners, since they also didn’t get it willingly, thus prefer to keep quiet about their status” [KII 03, Adult/ intensive adherence counsellor]

Some Find no Need to Disclose

Some adolescents noted that they had not seen a need to disclose their HIV status to others, as one of them explained:

“I have everything I need so I find no reason to reveal my secret” [IDI 15, 17yr male]

“I just don’t want others to know my status.” [IDI 03, 10yr female]

Health Facility Factors

Some health workers don’t encourage self-disclosure among adolescents, meaning that those adolescents don’t get reminders about the importance of self-disclosure.

“When we have long lines, one may rush seeing the adolescent and end up missing the important cues that may help disclosure” [KII 04, Doctor]

“When you find the adolescent has virally suppressed and doing well, we may sometimes tend to overlook the issue of disclosure not knowing they may be adhering due to different reasons” [KII 04, Doctor],

“Some health workers don’t consider disclosure important especially for those who are not sexually active.” [KII 05, Doctor]

Societal Factors

Involuntary disclosure was reported as a barrier to self-disclosure, because when the adolescents find their status disclosed to others, they have no chance to do it themselves but also feel anger and discouragement. For example:

“My whole family knows about my status, though I don’t know who told them; I felt angry that they knew and didn’t tell me.” [IDI 19, 15yr female].

One of our key informants also commented that, “I personally think most of these adolescents have not been given a chance to disclose; they have been disclosed for by other people. Like an S.5 boy who was escorted by a sister who said she would tell the head teacher and matron so that they give the boy special attention, despite the boy’s refusal” [KII 05, Doctor]

Discouragement by Parents and Family Members

Some parents and family members were said to discourage their children from disclosing their HIV status for fear of family stigma.

“I know a girl who disclosed her status to a friend

despite her mom discouraging her from telling others. Her parents were very annoyed...” [IDI 05, 15yr female]

Related to that, a key informant added:

“A child may want to tell their best friend but the parent tells them never to tell anyone, this is our secret.” [KII 05, Doctor]

Misconceptions about HIV in Society

“Most people think that HIV is brought by promiscuity; that makes you feel guilty despite getting it from parents.” [IDI 08, 17yr male]

“Some people have a negative attitude about people who have HIV”. [IDI 15, 17yr male]

Consequences of Self-Disclosure

There were positive and negative consequences reported by adolescents who had disclosed their HIV status to others.

Positive Consequences

Most of our participants reported that they had received financial, physical and emotional support from the people whom they disclosed to.

“My girlfriend escorts me to the clinic and remind me to take my medication” [IDI 16, 19yr, male].

Disclosed to best friend who was also positive, “we encourage each other to be happy and take our medicine” [IDI 13, 14yr female].

Many adolescents were virally suppressed, some achieved that after disclosure.

“I told my paternal aunt what I am (my status), then she told my dad who gives me transport ...but when my dad was told that I wasn’t taking medicine well, he said he would kill me himself. Now I take it well and the counsellor told me the virus is low” [IDI 02, 16yr female]

Some adolescents reported receiving education sponsorship following disclosure. “...a teacher who knew my status was asked for children on ART, she gave them my

name and they paid my fees” [IDI 02, 16yr female]

Happiness, freedom and wellness was reported upon disclosure to relatives at home. *“I am now happy, free, I have life and I don’t feel sad despite being HIV positive.”* [IDI 18, 17yr female] Another one also said she felt happy after self-disclosure to her sexual partner. [IDI 09, 19yr female]

Another positive outcome of disclosure was sensitizing friends on how to keep themselves safe from HIV. *“...she learnt that she should keep herself safe, and advise those who are sick to take their medicine to be well.”* [IDI 13,14yr female]

Some adolescents had become celebrities or ambassadors who could motivate others to live positively and some of them were free to disclose to the public. *“...we have Uganda Network of Young People Living with HIV/AIDS (UNYPA) an organization that sets-up beauty pageants for Mr/Miss Y+. One girl from Mbarara disclosed and was encouraged to adhere to treatment since she wanted to compete in the beauty pageant. Now she is Miss Y+”* [KII 06, male peer educator]

Negative Consequences

These were reported by many adolescents who had disclosed their HIV status, and some who were fearing to disclose because they had seen or heard about these negative outcomes in their society. Most reported stigma/rejection, others lost jobs, faced violence or developed depression.

Domestic violence was reported, *“I once received a phone call late at night, and the girl (adolescent)said....I have disclosed to this man but he wants to kill me, he has a knife. The girl was in tears and I didn’t know the man’s age”* [KII 06, male peer educator]

Rejection was reported by many participants, both from relatives and sexual partners. *“I told my family members, some were angry with me, none supports me”* [IDI 12, 19yr female] *“...some were chased away from home, others were rejected by friends at school/partners”* [KII 04, Doctor]

Some adolescents reported loss of jobs as one narrated.

“I was working as a maid but when my boss learnt that I had HIV, she didn’t pay my money. Other bosses abused me, tormented me and chased me away” [IDI 12, 19yr female]

Job loss was also reported by some key informants as one noted, *“Some adolescents have reported that they were working in some homes and when their bosses learnt about their status, they ended their employment time on short notice.”* [KII 07, female peer educator]

Some adolescents defaulted hospital visits following disclosure, *“...when I told boss that I had issues to sort at hospital, she wanted to terminate my job so I stopped coming to the clinic to keep my job”* [IDI 09, 19yr female]

One of the health workers also reported, *“Those working as house helps may miss appointments because they don’t want to disclose to their boss. It is a real challenge”* [KII 04, Doctor]

Depression was also reported, *“I haven’t told anyone because when others disclose I think they feel bad or even commit suicide”* [IDI 08, 17yr male].

A similar comment was made by many key informants including one who said,

“...they may get depressed, or tortured psychologically because of taking ART that some have had to change schools, while others had suicidal ideas” [KII 02, Doctor]

“Some developed negative coping mechanisms like alcohol/drug abuse” [KII 04, Doctor]

Some relatives cut support to the HIV positive child. *“...at my aunt’s place, they thought I was dirty and didn’t support me so I decided to go away and live with my grandmother”* [IDI 16, 19yr male]

One of the key informants also reported that some care takers stopped giving financial support following disclosure.

“Some relatives of these adolescents think that the child is going to die, so they stop giving them financial assistance.” [KII 03, Intensive adherence counsellor].

Discussion

In this study, half of the participants were female adolescents living with HIV, the median age was 16 years, and a few of them were total orphans while majority had virally suppressed. Only 2 in every five adolescents had disclosed their HIV status to another person who was either a friend, a relative or a sexual partner. This rate of self-disclosure is above what was reported by Nostlinger et al in a Uganda/ Kenya study [13].

Our findings show that adolescents tend to keep their status a secret. This is in line with findings of Nostlinger in study conducted in Baylor-Uganda and Western Kenya [13]. Sphiwe in South Africa also had similar findings and concluded that adolescents maintained secrecy in order to be accepted by their peers and prevent stigma and isolation [13,21].

The results revealed various facilitators of self-disclosure including; counselling at facility, need for support, developing trust over time, late adolescence age, acquiring information about HIV and disclosure as a way to prevent HIV transmission.

Among the key barriers to self-disclosure of HIV status were; stigma/rejection, fear of the unknown, protecting parents from shock/family stigma, partial disclosure by parents, lack of knowledge about HIV, need for HIV negative partners. Some of these barriers were also reported in WHO review paper about gender dimensions of HIV status disclosure to sexual partners, rates, barriers and outcomes [23].

The facilitators of disclosure included the following;

Need for support was reported by most of the participants in this study, as a reason for them to disclose to others. Self-disclosure can create opportunities for adherence, psychological and financial support from peers, sexual partners or family members. This is corroborated by findings by Nostlinger et al and Kajubi et al who found that intra-family communication patterns supported adolescents in medication use [13,24].

In this study, late adolescence, having a sexual partner(s), history of having had sex and/or a child, exposure to alcohol, and having attained secondary education and above were associated with self-disclosure. Most of these factors were found significant for disclosure which could be further explained by the increasing cognitive and reflective skills, which are linked to the adolescent maturation process. This was seen by Christiana Nostlinger, et al who also attributed their disclosure to an act of autonomy [13].

More females than male adolescents disclosed their HIV status to others probably due to the fact that men tend to avoid communication such as HIV disclosure and perceived that was highly personal information and want to protect family from shame. This finding is similar to what was stated by Lemin et al in Malaysia [25]. In contrast, a few studies reported that women are vulnerable to negative complication of HIV disclosure such as blame and physical violence from family and society; therefore, women were afraid to disclose. A report by WHO states lower rates of disclosure among women in developing countries [23].

Assisted partner notification (APN), one of the platforms present at MJAP clinic may explain the finding that more than half of our participants' partners were tested, and of the 39% found positive, 86.7% were in care. APN as a facilitator of self-disclosure was also requested by adolescents in study by Siu et al in Uganda [22], and also reported by a publication about a success story by Faridah Akuju in Kawempe Home Care [26], and a study in Kenya to augment HIV testing and linkage to care [27].

One of the participants aims at disclosing to individuals but also to make a public disclosure so as to assist various adolescents living with HIV to learn that you can live well when you are HIV positive, and life can continue. This is encouraged by UNYPA, an organization that sets-up beauty pageants for Mr/Miss Y+ to motivate young people to live positively, so some can disclose freely to the public.

The barriers to disclosure included the following;

Most adolescents who were found to have disclosure concern or negative self-feeling stigma were less likely to disclose since those who were found to have personalized stigma, were three times more likely to have disclosed their

HIV status to others. That was also expounded upon in the interviews, where adolescents feared discrimination and being devalued. In the study by Nostlinger et al, this was not found to be a significant predictor of self-disclosure [13] but reported negative attitudes by Siu et al in Uganda [22].

Adolescents who were not employed were less likely to disclose, maybe because working could result in more communication opportunities and subsequent disclosure, but also in reaching independence, which could include telling others about their status, be it voluntarily or not. This was comparable to findings by Nostlinger et al who reported that adolescents who contributed to family income were more likely to disclose [13].

Barriers to self-disclosure included parents discouraging their children from disclosing for fear of family stigma. That parental fear and perceived inability of adolescent to keep confidentiality was also found in a study by Mweemba et al in Zambia [28], and Kajubi et al in Uganda [24].

Many adolescents reported having multiple sexual partners. This posed a challenge to self-disclosure since some partners did not want to go to hospital for couple counselling and testing, so the adolescents also chose to find excuses or keep quiet about their status. This was similar to findings among young people living with HIV in Dar es Salaam who had risky sexual behavior [29].

The consequences of disclosure included;

In this study, adolescents and key informants reported some positive and negative consequences of self-disclosure. The positive consequences included; financial, emotional and physical support, good adherence on treatment, happiness and freedom with their sexual partners. Some of these were also reported by various scholars including Nostlinger et al in a study conducted in Uganda and Kenya [13]

Some participants reported negative consequences including; stigma (personalized or disclosure concern or public concern or negative self-feeling stigma), being faced with Gender Based Violence (GBV), loss of jobs, mental illness like depression and some defaulted treatment. These

are similar to findings reported by Siu et al, and reports about GBV in the WHO 2017 report [2].

Many barriers to self-disclosure have been overcome by platforms at the clinic, including; adolescent friendly services, adolescent fora, assisted partner notification, counselling, WhatsApp group for the young people to interact with peers from time to time, involving care takers in care and having home visits for some who miss clinic appointments.

Other suggested ways to overcome rejection/stigma included; more adolescent friendly health workers, empowerment of the adolescents to be assertive, a step-by-step guide to self-disclosure, all stakeholders in the country ought to play their part to sensitize masses and discourage stigma/rejection of people living with HIV, implementing partners ought to construct a home where rejected adolescents can be taught skills to be independent then later be re-connected to their relatives meanwhile they may be connected to Wakisa ministries, or Action Aid.

Strengths and limitations of the study

Strength: This is one of the few studies exploring facilitators, barriers and outcomes of self-disclosure among ALHIV in the era of 'Test and treat'. Mixed methods enabled triangulation of factors among adolescents and health workers or key informants.

Limitations: During piloting of the study tools, the question on form of acquisition of HIV was not clearly understood, since some adolescents hesitated to answer it, others said they were not sure and we did not have means to confirm the source of HIV acquisition. Thus the question was dropped and we were unable to compare disclosure patterns among adolescents who acquired HIV horizontally/vertically. However, some key informants commented on those patterns. More studies may be required to assess the relationship between mode of transmission of HIV to the adolescents and self-disclosure.

This was a cross-sectional study, meaning we could not relate what came first in some cases like those of risky sexual/drugs behavior, depression, nor have direct control over parental disclosure to the adolescents. Other

studies will be needed to assess the relationship between cause and effect of self-disclosure among adolescents.

Conclusion and Recommendations

The rate of self-disclosure in this study was quite low at 46%, with need for support as a major facilitator and stigma as a major barrier to self-disclosure reported by the adolescents and key informants.

Based on our findings, we recommend that adolescents attending MJAP clinic, and those in other HIV clinics in Uganda need to be supported to disclose their HIV status in order for them to achieve the benefits of self-disclosure, overcome stigma and thus reduce transmission of HIV among adolescents. This could be through increased sensitization of masses about HIV stigma by key stakeholders like policy makers, community health extension workers and health workers.

There is need for further research to study how these facilitators and barriers vary among those who acquired infection via vertical or sexual transmission routes.

Acknowledgments

The Almighty God for this far He has brought me!
For His guidance, wisdom, abundant grace and love.

My dear supervisors; Dr. Opoka, Dr. Sabrina, Dr. Ombeva and Dr. Rujumba who have supported, mentored and guided me in the project!

The staff at MJAP- ISS clinic, especially the clinic director Dr. Semitala who accepted me to carry out the project there, clinic manager Ms. Nansubuga for guidance and support, my research assistants Kizza Lubega, Christine, Immaculate for tirelessly assisting with the data collection and editing when need arose, key informants and participants for cooperating as they shared information during the research project.

My sponsors (various individuals with no influence to the findings), my husband, family, and friends for the support, care, understanding and believing in me thus far.

References

1. UNICEF (2019) Adolescent HIV prevention. Turning the tide against AIDS will require more concentrated focus on adolescents and young people.
2. WHO (2017) the Joint United Nations Programme on HIV and AIDS (UNAIDS), in Guidelines for second generation HIV surveillance. Geneva: UNAIDS, World Health Organisation: Geneva.
3. Bearinger LH, et al. (2007) Global perspectives on the sexual and reproductive health of adolescents: patterns, prevention, and potential. *The Lancet*, 369: 1220-31.
4. Mburu G, et al. (2014) Adolescent HIV disclosure in Zambia: barriers, facilitators and outcomes. *Journal of the International AIDS Society*, 17: 18866.
5. Pathak S, (2012) Parental monitoring and Self-disclosure of Adolescents. *Journal of Humanities and Social Science*, 5: 1-5.
6. Buhrmester D, K Prager, (1995) Patterns and functions of self-disclosure during childhood and adolescence.
7. Sherman BF, et al. (2000) When children tell their friends they have AIDS: possible consequences for psychological well-being and disease progression. *Psychosomatic medicine*, 62: 238-47.
8. Laurenceau JP, L Barrett, P Pietromonaco, (2004) Intimacy as an interpersonal process: The importance of self-disclosure, partner disclosure, and perceived partner responsiveness in interpersonal exchanges. *Close relationships: Key readings*, 2004: 199-211.
9. Smith R, K Rossetto, BL Peterson, (2008) A meta-analysis of disclosure of one's HIV-positive status, stigma and social support. *AIDS care*, 20: 1266-75.
10. Act, T.H.A.P.C. (2014) Kampala UGANDA.
11. UNAIDS, (2013) The People Living With HIV Stigma Index, T.N.F.o.P.L.w.H.N.i. Uganda, Editor. Kampala, Uganda. 14.
12. Bakeera-Kitaka S, et al. (2008) Sexual risk reduction needs of adolescents living with HIV in a clinical care setting. *AIDS care*, 20: 426-33.
13. Nöstlinger C, et al. (2015) Factors influencing social self-disclosure among adolescents living with HIV in Eastern Africa. *AIDS care*, 27: 36-46.
14. Judd A, et al. (2007) Morbidity, mortality, and response to treatment by children in the United Kingdom and Ireland with perinatally acquired HIV infection during 1996–2006: planning for teenage and adult care. *Clinical infectious diseases*, 45: 918-24.
15. MOH (2018) Uganda Clinical Guidelines, Kampala Uganda: Ministry of Health.
16. Hazen E, S Schlozman, E Beresin, (2008) Adolescent psychological development: a review. *Pediatr Rev*, 29: 161-7.
17. Abadia-Barrero CE, A Castro, (2006) Experiences of stigma and access to HAART in children and adolescents living with HIV/AIDS in Brazil. *Soc Sci Med*, 62: 1219-28.
18. Calabrese SK, et al. (2012) Diagnosis disclosure, medication hiding, and medical functioning among perinatally infected, HIV-positive children and adolescents. *AIDS care*, 24: 1092-6.
19. Mofenson LM, MF Cotton, (2013) The challenges of success: adolescents with perinatal HIV infection. *J Int AIDS Soc*, 16: 18650.
20. Rao D, et al. (2007) Stigma and social barriers to medication adherence with urban youth living with HIV. *AIDS Care*, 19: 28-33.
21. Madiba S, M Mokgatle, (2016) Perceptions and Experiences about Self-Disclosure of HIV Status among Adolescents with Perinatal Acquired HIV in Poor-Resourced Communities in South Africa. *AIDS Res Treat*, 2016: 2607249.
22. Siu GE, et al. (2012) HIV serostatus disclosure and lived experiences of adolescents at the Transition Clinic of the Infectious Diseases Clinic in Kampala, Uganda: a qualitative study. *AIDS Care*, 24: 606-11.
23. WHO (2004) Gender dimensions of HIV status disclosure to sexual partners: rates, barriers and outcomes.

World Health Organization.

24. Kajubi P, et al. (2014) Communication between HIV-infected children and their caregivers about HIV medicines: a cross-sectional study in Jinja district, Uganda. *J Int AIDS Soc*, 17: 19012.
25. Lemin AS, MM Rahman, CA Pangarah, (2018) Factors Affecting Intention to Disclose HIV Status among Adult Population in Sarawak, Malaysia. *J Environ Public Health*, 2018: 2194791.
26. Nöstlinger C, et al. (2006) Children and adolescents living with HIV positive parents: Emotional and behavioural problems. *Vulnerable Children and Youth Studies*, 1: 29-43.
27. Levy ME, et al. (2016) Low social support and HIV-related stigma are highly correlated among adolescents living with HIV in Western Kenya. *Journal of Adolescent Health*, 58: S82.
28. Mweemba M, et al. (2015) "When am I going to stop taking the drug?" Enablers, barriers and processes of disclosure of HIV status by caregivers to adolescents in a rural district in Zambia. *BMC Public Health*, 15: 1028.
29. Mhalu A, GH Leyna, EJ Mmbaga (2013) Risky behaviours among young people living with HIV attending care and treatment clinics in Dar Es Salaam, Tanzania: implications for prevention with a positive approach. *J Int AIDS Soc*, 16: 17342.

Submit your manuscript to a JScholar journal and benefit from:

- ¶ Convenient online submission
- ¶ Rigorous peer review
- ¶ Immediate publication on acceptance
- ¶ Open access: articles freely available online
- ¶ High visibility within the field
- ¶ Better discount for your subsequent articles

Submit your manuscript at
<http://www.jscholaronline.org/submit-manuscript.php>