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Modality of Primary HIV Disclosure and Association with Mental Health, Stigma, and Antiretroviral Therapy Adherence in Tanzanian Youth Living with HIV

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Abstract

Disclosing HIV status to children before adolescence is a major challenge facing families and healthcare providers. This study used a mixed methods approach to explore the youth perspective of how youth living with HIV (YLHIV) found out their status and to quantify the association of disclosure modality with mental health, stigma, adherence, and HIV outcomes in adolescence. Youth 11–24 years of age attending adolescent HIV clinic in Moshi, Tanzania were included. Adolescents answered questions, including when and how they found out they had HIV, mental health surveys (nine-item Patient Health Questionnaire, Strengths and Difficulties Questionnaire, and modified University of California Los Angeles trauma screen), modified Berger's stigma scale, and self-reported adherence. HIV-1 RNA and latest CD4 were obtained. In-depth interviews were conducted using a convenience sample. The majority of youth reported that they found out their HIV status on their own (80%). Youth attending the government site were less likely to be purposefully told their HIV status compared with those attending the referral site ($p < 0.01$). Depressive and emotional/behavioral symptoms, internal stigma, and incomplete adherence were significantly more likely among those who figured out their HIV status on their own as compared with those who were purposefully told. Youth discussed how they figured out their HIV status on their own during in-depth interviews. These findings demonstrated that youth who figured out their HIV status on their own had increased mental health symptoms and worse adherence to antiretroviral therapy (ART). It is imperative to implement disclosure protocols in early childhood to reduce mental health difficulties, internal stigma, and promote ART adherence in YLHIV.

Keywords: HIV, adolescents, disclosure, mental health, stigma, adherence

Introduction

At the end of 2013, there were an estimated 4 million youth 15–24 years of age living with HIV.[1] Approximately 80% of these youth live in sub-Saharan Africa, where the majority acquired HIV perinatally.[1–4] As antiretroviral therapy (ART) becomes more accessible, the number of children with HIV surviving to adolescence continues to grow,[4] bringing new challenges to maintaining their health and wellbeing. Disclosing HIV status to children before reaching adolescence is a major challenge facing families and healthcare providers who care for HIV-infected children.[5–7]

Disclosure of a child's HIV status is a process that should parallel cognitive development.[8–16] The World Health Organization recommends the process of HIV disclosure begin and be completed during the age of primary school (6–12 years of age).[17] Parallel to cognitive development, a child should move from partial disclosure to full disclosure, gradually building an understanding of their illness, and why they take medication.

The rate of full disclosure in low- and middle-income countries is low for a variety of reasons, including challenges faced by the healthcare provider and caregiver.[18,19] Healthcare providers and caregivers desire to protect children from being overwhelmed or stressed[20]; they may fear children are too

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young to understand.[12] HIV is also uniquely associated with social stigma.[21,22] In addition, disclosing the HIV status to a child may involve the indirect disclosure of the positive HIV status of the child's mother.[14] In this situation, the caregiver may fear being judged by the child if the caregiver is the biological mother, or fear that the child will tell others and that the family will be stigmatized by the community.[13,14,23–25]

Few studies have reported disclosure status from the youth's perspective.[22,26–29] Most disclosure literature reports on HIV disclosure from the perspective of the healthcare provider or caregiver's impression of what they think the child or youth understands.[30–34] Children, however, reach a point in their cognitive development, where increased social awareness and curiosity leads them to figure out their HIV status, despite caregivers' attempts to protect them from knowing their HIV diagnosis.[18,35] Those with extended periods of silence or secrecy regarding their HIV status may isolate themselves from social support, experience increased mental health difficulties, internal stigma, adherence problems, and may also feel cynical toward their future with distrust of their HIV care provider and poor understanding of the implications of HIV/AIDS in their lives.[12,14,22] The present study sought to explore the youth perspective and quantify the association of modality of primary disclosure on stigma, mental health, adherence, HIV outcomes, and the psychosocial context among youth living with HIV (YLHIV) in Tanzania.

Methods

This is a mixed methods study that took place in Moshi, Tanzania at two health centers, Kilimanjaro Christian Medical Center (KCMC), a tertiary referral hospital, from December 2013 through May 2014, and Mawenzi Regional Referral Hospital (MRRH), a government hospital from February 2015 to July 2015.[36,37] Both hospitals have an adolescent HIV clinic, where youth 11–24 years of age meet once each month to receive medical care and peer support. Inclusion criteria for study participants included youth 11–24 years of age who were aware of their HIV diagnosis and engaged in routine outpatient HIV care at KCMC or MRRH. Youth living in orphanages or other institutions, or with a developmental disability or cognitive impairment significant enough to limit the youth's understanding of study procedures were excluded. Youth who were not yet receiving ART were excluded from self-reported adherence measures and HIV-1 RNA analyses. HIV-1 RNA was drawn prospectively and virologic failure was defined as ≥400 copies/mL. The latest CD4 (within 6 months of survey) was obtained retrospectively from the participant's clinical file.

Participants completed an interview-assisted structured questionnaire in Swahili regarding demographics, identity of caregiver, living status of biological parents, mode of primary HIV disclosure, ART adherence, stigma, and mental health difficulties. A convenience sample of 62 youth attending KCMC returned for an in-depth interview; 34 in-depth interviews were translated with content saturation regarding how the youth found out their HIV status. The structured questionnaire and the in-depth interview guide were translated to Swahili and back-translated to English by two different native-speaking research assistants.

Measures

Adherence. Self-reported adherence was measured using two questions in the structured questionnaire: (1) dichotomous "Have you missed any medication doses in the past 2 weeks?" Yes or No and (2) categorical "Many people miss their medication. Think about the past week (7 days). On average, how often did you miss a dose of medication?" once a day, more than once a week, but not every day, once a week, and I do not miss my ART medicine. Any endorsement of missing ART was analyzed as poor adherence.

Stigma and mental health. Both internal and external levels of stigma were evaluated using 10 questions from a modified Berger's HIV Stigma Scale (possible scores range 10–40).[38]

Depressive symptoms were measured using the nine-item Patient Health Questionnaire (PHQ-9). Possible scores range from 0 to 27. This study used a score ≥10 to reflect moderate-to-severe depressive symptoms.[39–41]

Behavioral and/or emotional symptoms were assessed using the Strengths and Difficulties Questionnaire (SDQ). Possible SDQ scores range from 0 to 40 and a threshold ≥17 was utilized to indicate the presence of behavioral and/or emotional symptoms.[42]

Posttraumatic stress disorder (PTSD) was screened using the University of California Los Angeles PTSD Exposure questionnaire, which has been used to screen for PTSD symptoms in school-age children and adolescents. This study modified the tool's 5-point response scale to a 4-point response scale: (0) none; (1) little; (2) much of the time; or (3) most of the time, removing the option "some of the time" due to translation difficulties in Swahili. Possible scores on this modified scale ranged from 0 to 51.[43] The threshold for posttraumatic stress symptoms was ≥18.[44]

Disclosure. Youth were asked about their disclosure experience using the following questions: (1) "When did you first find out you were HIV positive?" with a year or age provided; (2) "How did you first learn you were HIV positive?" (a) I overheard people talking, (b) I figured it out on my own, and (c) I was purposefully told; and (3) "Who purposefully told you?" (a) family, (b) healthcare provider, (c) friend, (d) teacher, and (e) self (i.e., was never purposefully told). For the quantitative analysis, I overheard people talking and I figured it out on my own, were combined as I figured it out on my own.

A subset of youth completed in-depth interviews. Youth were asked to elaborate further on their primary disclosure experience, whether they had been expecting the news of their positive HIV status and how they reacted to the news of the disclosure.

Data analyses

Descriptive statistics were used to summarize demographics, disclosure, mental health, stigma, HIV measures, and adherence. Pearson's chi-square test was used to compare dichotomous variables between those purposefully told and those who figured out themselves and Wilcoxon rank-sum test was used to compare continuous variables. STATA Data Analysis and Statistical Software 14.2 (College Station, TX) was utilized for all statistical analyses.

Two research assistants fluent in Swahili and English transcribed and translated 34 interview recordings. Microsoft Excel was used to maintain data and conduct qualitative analysis. After translation, two team members wrote memos using a grounded theory approach.[45] Memos were then discussed among four team members to ensure reliability and cohesion. Memos were coded for themes specific to the concept of mode of primary disclosure.[46] As themes emerged, direct quotations were obtained from the transcript.

Ethics

Informed consent was obtained from all participants 18 years or older. For youth under 18 years, a parent or guardian provided consent for the youth's participation, and the youth provided assent. The study protocol was approved by the Duke University Medical Center Institutional Review Board, the KCMC Research Ethics Committee, and the Tanzanian National Institute for Medical Research.

Results

Two hundred eighty participants were included in the study. Eighty percent of youth ($n=223$) figured out their HIV diagnosis on their own. Although over half were eventually told their diagnosis by a healthcare worker (55%) or family member (33%), most had already figured out their diagnosis before purposeful disclosure. Demographic comparisons based on mode of HIV disclosure (''purposefully told'' vs. ''figured it out'') are described in Table 1. The median age of participants at the time of survey was 16.3 years and the median age at time of disclosure was 12.0 years. The majority of youth (>75%) experienced the death of one or both parents. For demographic measures, only clinic site was significantly different between groups, where those who first learned their HIV status by purposeful disclosure were more likely to be attending KCMC as compared with MRRH adolescent clinic ($p<0.001$).

Those meeting a dichotomous threshold of depressive symptoms (PHQ-9 ≥ 10) and emotional/behavioral symptoms (SDQ ≥ 17) were more likely to have found out their HIV diagnosis on their own versus being purposefully told ($p<0.001$; Table 2). On a continuous scale, youth who figured out their HIV status on their own had significantly increased scores on all three mental health measures, including posttraumatic stress symptoms ($p<0.001$) and increased internal stigma ($p<0.01$), compared with those who were purposefully told their HIV diagnosis.

Of the 248 youth receiving ART with a viral load result, over 40% had virologic failure (≥400 copies/mL) and approximately one-third (32.4%) of youth reported poor ART adherence (Table 3). There was no evident difference between the CD4 counts nor virologic failure among those who were purposefully told their HIV diagnosis versus those who figured it out on their own. However, those who figured out their HIV status on their own were more likely to have

Table 1. Comparison of Youth Demographics Based on Mode of Disclosure

	Total, n=*280*	*Purposefully told,* n=*57 (20%)*	*Figured out on own,* n=*223 (80%)*	p
Age at time of survey, median [IQR]	16.3 [14.7–18.6]	15.9 [14.5–18.3]	16.4 [14.7–18.6]	0.55
Age at disclosure, *n*=216, median [IQR]	12.0 [10.2–13.8]	12.3 [9.6–13.7]	12.0 [10.3–13.8]	0.65
Gender (female), *n* (%)	155 (55.4)	29 (50.9)	126 (56.5)	0.45
Living status of biological parents, *n* (%)				
Both parents living	68 (24.3)	14 (24.6)	54 (24.2)	0.57
One parent deceased	128 (45.7)	29 (50.9)	99 (44.4)	
Both parents deceased	84 (30.0)	14 (24.6)	70 (31.4)	
Caregivers, *n* (%)				
Parent	125 (44.6)	25 (43.9)	100 (44.8)	0.89
Aunt/uncle	71 (25.4)	13 (22.8)	58 (26.0)	
Grandparent	60 (21.4)	13 (22.8)	47 (21.1)	
Sibling	13 (4.6)	4 (7.0)	9 (4.0)	
Unknown	11 (3.9)	2 (3.5)	9 (4.0)	
Tribe, *n*=279, *n* (%)				
Chaga	183 (65.6)	35 (61.4)	148 (66.4)	0.57
Pare	28 (10)	9 (15.8)	19 (8.5)	
Sukuma	5 (1.8)	1 (1.8)	4 (1.8)	
Other	63 (22.5)	12 (21.0)	51 (22.9)	
Attending school, *n* (%)	213 (76.1)	47 (82.5)	166 (74.4)	0.21
Clinic site, *n* (%)				
KCMC	182 (65.0)	54 (94.7)	128 (57.4)	<0.001
Mawenzi	98 (35.0)	3 (5.3)	95 (42.6)	
Antiretroviral therapy, *n* (%)				
None	20 (7.1)	7 (12.3)	13 (5.8)	0.153
NNRTI-based	191 (68.2)	34 (57.9)	157 (70.0)	
PI-based	69 (24.6)	16 (29.8)	53 (24.2)	

Count (%) reported unless otherwise stated.

IQR, interquartile range; KCMC, Kilimanjaro Christian Medical Center; NNRTI, non-nucleoside reverse transcriptase inhibitor; PI, protease inhibitor.

Table 2. Association of Youth Mental Health and Stigma with Mode of Disclosure

	Total, n = *280*	*Purposefully told,* n = *57 (20%)*	*Figured out on own,* n = *223 (80%)*	p
Dichotomous mental health measures, *n* (%)				
PHQ-9 (≥10)	57 (20.4)	4 (7.0)	53 (23.8)	<0.001
SDQ (≥17)	48 (17.1)	2 (3.5)	46 (20.6)	<0.001
Trauma (≥18)	37 (13.2)	5 (8.8)	32 (14.3)	0.38
Continuous mental health measures, median [IQR]				
PHQ-9	4 [1–8.5]	1 [0–4]	5 [2–9]	<0.001
SDQ	10 [6–14]	5 [3–8]	11 [7–15]	<0.001
Trauma	7 [3–13]	5 [1–9]	8 [4–14]	<0.001
External stigma, median [IQR]	13 [12–17]	13 [11–16]	13 [12–17]	0.33
Internal stigma, median [IQR]	6.5 [4–8]	4 [4–8]	7 [5–8]	<0.01

PHQ-9, nine-item Patient Health Questionnaire; SDQ, Strengths and Difficulties Questionnaire.

incomplete adherence compared with those who were purposefully told ($p = 0.04$).

Qualitative results

A convenience sample of interviews from 34 KCMC youth was analyzed. Youth described in detail how they learned their status. While some youth explained that they overheard someone talk about their HIV diagnosis, others described how they took initiative to better understand their health and why they were receiving daily medication.

One participant described her education at clinic to be how she found out her HIV status.

> Interviewer (I): How did you know?
> Participant (P): When I was taking medicine, I heard from other people who were talking. That's when I knew my status.
> I: I mean, I want to know who told you?
> P: Nobody told me…Even mother did not tell me.
> I: How about nurses?
> P: Yes, the way nurses were talking that's when I knew.
> I: Did they call you in a private room and tell you?
> P: No

Another youth described how she created a story to convince a pharmacist to explain the purpose of her medication.

> P: In that one big pharmacy in town, this day…I had written down the name [of my medicines] on a piece of paper. And then I went and said, ''Excuse me,'' I greeted them and then I asked, ''Do you all know what this medicine does?'' They told me, ''What do you want it for?'' I then told them that my science teacher asked us to ask other people about the use of this medicine and on Monday, we should bring our answers [to class]. So, then they told me.

Another youth explains how he grew impatiently curious and searched through medical files at home.

> P: Many times, I was curious because I had been taking medicines even though I did not know what they were for. So, I tried to investigate from the father I am living with. Since they lied to me, saying that I am suffering from the chest, I asked ''how come I do not cough but I am still using medicines?'' Still they never told me. After, it bothered me a lot. Later, I searched father's files at home. I found a paper with my name and my results written on it. That's when I found out.

Some youth spoke about the emotions they experienced when they found out their HIV status on their own.

One youth talked about how he felt that he had been lied to for years.

> I: How did you feel?
> P: I was tired, because I prefer they would have told me earlier so that I would have known for myself my problem rather than them lying to me…I was angry.

When youth were asked to describe how they reacted to the news of their HIV diagnosis, most used the word ''normal'' to describe how they felt.

Some youth situate the normalcy in understanding, where they communicate empathy toward their caregiver and the challenging position their caregiver was in when they were deciding how to disclose.

> P: … Later I realized it was normal, because parents can experience fear [when they think about disclosing to their

Table 3. Youth Physical Health Status and Adherence Association with Mode of Disclosure

	Total, n = *280*	*Purposefully told,* n = *57 (20%)*	*Figured out on own,* *n = 223 (80%)*	p
CD4, median [IQR]	532 [316–764]	519 [269–693]	539 [320–793]	0.27
HIV-1 RNA >400 copies/mL (*n* = 248), *n* (%)	103 (41.5)	23 (40.4)	80 (35.9)	0.39
Self-reported poor ART adherence (*n* = 259), *n* (%)	84 (32.4)	10 (17.5)	74 (33.2)	0.04

ART, antiretroviral therapy.

> child], ''how will I begin to tell them?'' or ''how will I be able to tell them?'' so I then realized it was normal.

While other youth described that they needed to feel normal since there is nothing they can do to change their HIV diagnosis.

When asked whether youth were expecting the news that they were HIV positive when their healthcare provider disclosed to them, most said that they were expecting the news.

> I: And then, when you were given your results here at KCMC by the doctors that you had this problem, were you expecting it?
> P: Yes

Discussion

This study uniquely explored the impact of disclosure modality on the wellbeing of youth. The majority of youth were not purposefully told their HIV status early and many consequently found out their HIV status on their own, before purposeful disclosure. To our knowledge, this is the first article to describe the association of youth figuring out their HIV status on their own with increased internal stigma, worse ART adherence, and increased mental health difficulties as compared with youth who were purposefully told. This study captured the nuanced stories of how YLHIV found out their HIV status and provided a snapshot of disclosure impact in adolescence.

Within their disclosure accounts, youth felt like they were being lied to, a theme in accordance with previous studies. In a review of HIV disclosure, including 22 studies in 12 low- and middle-income countries, nearly half (49.5%) of children were provided information about their less stigmatizing diagnoses such as asthma or cancer, but not about HIV diagnoses.[47] Similarly, another study reported that 80% of children (8–15 years of age, mean age 13 years) enrolled in the University of Puerto Rico Pediatric HIV/AIDS Research Program had received news of their other diagnoses, such as heart disease or cancer, but no information concerning their HIV diagnosis.[18]

From a system's perspective, it was evident that differences in clinic procedures regarding early disclosure mattered to the wellbeing of YLHIV. Youth who figured out their HIV status on their own were more likely to attend MRRH adolescent clinic as compared with KCMC. To transition to adolescent clinic, it is mandatory that healthcare providers ensure that youth understand their HIV diagnosis. The KCMC adolescent clinic was founded in 2007 as compared with the MRRH adolescent clinic that started in 2014; thus, 30% of youth received purposeful disclosure at KCMC compared with 3% of youth at MRRH. These results are in line with a systematic review of HIV disclosure that found the range in rates of fully disclosed children to be between 1.7% and 41%.[47] Attention must focus not only on early disclosure, but also getting HIV-exposed children tested and those positive into care. The rate of HIV testing in HIV-exposed children in Tanzania and other low-resource settings is low.[48] This delay in testing and diagnosis of children further postpones the child's linkage to appropriate healthcare services.[49]

Youth in this Tanzanian study and a study from the University of Puerto Rico strove to normalize their disclosure experience and its associated negative emotions of anger, internal stigma, and loneliness. The qualitative interviews demonstrated the ability of youth to empathize with and forgive caregivers. Similar to other studies, many youth recognized that the process of disclosure may have been daunting for caregivers, many of whom had experienced their own trauma, stigma, and grief regarding their own infection with HIV or that of family members.[14,23–25] Youths' abilities to normalize, and empathize were strengths demonstrated in in-depth interviews and may be leveraged in future interventions aimed to improve early disclosure and empower youth.

This study had several limitations. The translated in-depth interviews were obtained from 34 YLHIV at KCMC and may not be representative of all YLHIV. Psychosocial reasons for delayed disclosure to youth who figured out their HIV status on their own, such as strained youth and caregiver relationships or frequent change in caregiver, were not deeply explored. Age of disclosure was subject to youth recall. Self-report of poor adherence was statistically different between disclosure groups; however, the definition of poor adherence was very strict. If a youth reported any missed dose, they were considered to have poor adherence. It has since been demonstrated that missing an occasional dose of ART may not jeopardize virologic suppression.[50,51] Virologic failure and CD4 were not statistically different between disclosure groups and reasons may be due to poor sensitivity of CD4 and potentially the presence of resistance mutations in otherwise adherent youth. This study did not track the number of youth who chose not to participate, thus there is limited data regarding differences between youth who agreed to study participation and those who chose not to participate. Finally, mental health screening tools were derived from Western constructs. Although they have been validated in neighboring countries, none has been validated in this specific population of Tanzanian adolescents living with HIV.

Overall, this study underscores the importance of beginning the HIV disclosure process with children early and monitoring their psychosocial wellbeing closely.[14,17] Children are able to understand concepts of health and illness;[35] therefore, it is important to empower them with knowledge of their HIV status and with education about HIV so that they are able to cope with their disease, better adhere to their medication, and live long and fulfilling lives. Over 40% of youth in this study had virologic failure, an alarming number reflecting the urgent need to address factors that impact ART adherence, many of which stem from psychosocial difficulties.[36,52] Additional training and implementation of guidelines and protocols to support healthcare providers and caregivers in disclosing HIV status to children are urgently needed. The experience of HIV disclosure can be a traumatic event for youth and should be addressed and discussed to improve coping and build resilience in YLHIV. Findings from this study were used in the development of Sauti ya Vijana (The Voice of Youth), a mental health group intervention to improve coping strategies using tools such as the cognitive behavioral triangle to support mental health, reduce stigma, increase social support, improve adherence, and to introduce strategies for secondary disclosure in YLHIV.

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Author Disclosure Statement

No potential conflict of interest was reported by the authors.

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