


RESEARCH ARTICLE

“My mother told me that I should not”: a qualitative study exploring the restrictions placed on adolescent girls living with HIV in Zambia

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Abstract

Introduction: Adolescent girls in sub-Saharan Africa are disproportionately affected by HIV due to a range of social and structural factors. As they transition to adulthood, they are recipients of increasing blame for HIV infection and ‘improper’ sex, as well as increasing scrutiny, restrictions and surveillance. This study used a qualitative and participatory approach to explore the messaging and restrictions imposed on adolescent girls living with HIV in Zambia.

Methods: Thirty-four in-depth interviews and four participatory workshops were carried out with 24 adolescent girls aged 15 to 19 years old living with HIV in Lusaka, Zambia. Key themes explored included experiences living with HIV, finding out about HIV status, disclosure, experiences with antiretroviral treatment, and support needs. Data were organized, coded and analysed using a grounded theory approach to thematic analysis. This analysis uses data on participants’ experiences of living with HIV and their interactions with their parents, guardians and healthcare providers.

Results: Family and healthcare providers, partly in a quest to protect both the health of adolescent girls living with HIV and also to protect them from blaming discourse, imposed restrictions on their behaviour around three main topics: *don't* disclose your HIV status, *don't* have sex, and *don't* miss your medicines. These restrictions were often delivered using tactics of fear, and usually disconnected from other options. Participants responded to these messages in several ways, including internalizing the messages, changing their behaviour either to comply with or resist the restrictions, by remaining silent and anxious when restrictions were broken, and developing concerns around their own health and sexual and reproductive aspirations. Participants also sometimes experiencing stigma when restrictions could not be maintained.

Conclusions: Restrictive messages were delivered to adolescent girls living with HIV through the broader social discourses of stigma, religion, and global and local narratives about HIV. Programmes aiming to support adolescent girls living with HIV need to work together with parents and healthcare providers to reflect on the impact of sanctioning messages, and to encourage more enabling and empowering messaging for adolescent girls living with HIV.

Keywords: Adolescents; stigma; adherence; social support; young women; adolescent girls; adolescents living with HIV; disclosure; sexual relationships; Zambia

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1 | INTRODUCTION

The importance of adolescent health is increasingly being recognized in sub-Saharan Africa [1-3], although the focus on preventing new HIV infections means that the needs of adolescents living with HIV (ALHIV) are not receiving sufficient attention [4]. With increasing access to effective antiretroviral therapy (ART) enabling vertically infected children to survive [5,6], alongside high incidence rates particularly amongst girls aged 15 to 19 years [7-11], adolescents are now a key group in sub-Saharan Africa affected by HIV. An estimated 2.1 million adolescents aged 10 to 19 years are living with HIV globally, including 79,000 in Zambia [12,13],

with more girls than boys infected. Nearly 6% of girls aged 15 to 19 in Zambia are living with HIV, around twice the proportion of adolescent boys of the same age [14].

Adolescents living with HIV across sub-Saharan Africa have been the subjects of narratives focused on ‘promiscuity’, personal blame and shame, and the circumstances of infection, based on global, local, religious and familial discourses around HIV [15-19]. Even with widespread access to ART, HIV-related stigma remains pervasive in many settings [15,20,21]. Despite the majority of ALHIV having been perinatally infected, connotations associated with shame and ‘improper sex’ also apply, and typically emerge during adolescence [15]. The combination of being young, female and having a highly

stigmatized disease that is mainly perceived to be transmitted sexually, drives morality narratives for adolescent girls living with HIV.

Adolescence is a period of transition from being viewed as a child to an adult, with increasing autonomy and responsibility, but alongside restrictions, rules and expectations regarding social behaviours [1]. Young women in particular are often restricted in their activities [22-24]. ALHIV have been described as developing increased levels of self-surveillance to fit in alongside their peers [25]. Increased care and surveillance from family members and healthcare providers is often protective but heightens the onus on restrictions and self-control [26]. The messages that ALHIV receive, and the restrictions that they are placed under, warrants more scrutiny. It is important to understand how these restrictions influence the parameters within which ALHIV behave and make choices, in order to better target interventions to provide information, support and empower choice. Focusing on the transition from adolescence to adulthood, we used a qualitative and participatory approach to explore the experiences of adolescent girls growing up with HIV in Lusaka, Zambia.

2 | METHODS

2.1 | Study population

Twenty-four adolescent girls living with HIV between the ages of 15 and 19 were recruited to participate in the study from two urban, government health facilities in Lusaka. One health facility was located in a high-density area, serving a predominantly low-income population, and the other was a centre for paediatric excellence accessed by a mixed-income population. Participants were recruited at the health facilities during paediatric ART days. All participants underwent an informed written consent process: for participants under 18 years old, informed written consent was sought from their parents or guardians first, and then informed written assent was sought from the participants; for participants over 18 years, their informed written consent was sought. As a condition of participation, all parents and guardians and all participants were aware of the HIV status of the participant for whom they provided consent.

2.2 | Data collection and analysis

Data were collected between January and April 2015 through a total of four participatory workshops and 34 in-depth interviews (IDI). First, four 6-hour participatory workshops were held with two groups of 10 and 14 participants each. Participatory tools, including concept mapping [27], collages [28] and vignettes [29] were used in the workshops. Two rounds of IDIs were then conducted with 17 participants purposefully selected from the workshops. The IDIs used 'network tools' [30] to describe the participants' 'affective networks' of who knew their HIV status, and their 'effective networks' of who provided them with support. The workshops gathered collective narratives from group interactions, while the IDIs provided the opportunity for participants to share in-depth individual experiences and, for some participants, to share traumatic experiences.

In both the workshops and IDIs, participants discussed finding out about their HIV status, experiences with disclosure, experiences with treatment and at the ART clinic, and support needs. All participants knew the research was only open to adolescent girls living with HIV: at the start of the workshops, a discussion was held about shared confidentiality. The workshops gathered collective narratives from group interactions, while the IDIs provided the opportunity to gather in-depth data on some individual experiences. Three trained counsellors (SC, CC, MC) and one young woman living with HIV were involved in the research design, data collection and analysis. Data were captured through audio recording, transcription and translation of interviews, note taking in the research workshops and photos of workshop materials. In research notes and transcriptions, pseudonyms were used to protect participant anonymity. Audio recordings were deleted after transcription. Visual data were stored in a locked cabinet accessible only to the research team. After the research ended, and based on requests from research participants, nine support group sessions with each group of the same participants, stretching over a period of a year were held.

Data were organized and coded using ATLAS.ti Version 7. We used a grounded theory approach to thematic analysis, using analytical memos to develop ideas. Visual data were analysed by physically grouping the collages and network diagrams into inductive themes. Using an inductive approach to analysis, the theme of restricting messages and the responses of participants to these messages emerged from the data, rather than being a predetermined theme.

2.3 | Ethical clearance

Ethical clearance for the study was obtained from the review boards of the International Center for Research on Women in Washington, DC, USA, and the University of Zambia Humanities Research Ethics Committee in Lusaka, Zambia. Permission to conduct the study was also given by the Ministries of Health in Zambia. London School of Hygiene and Tropical Medicine ethics committee granted permission for analysis of the data.

3 | RESULTS

3.1 | Participant characteristics

Participants ranged from age 15 to 18 years, with the majority (14 of 24) aged 15 to 16 years. The majority of participants were in school at the time of the study, with one not in school due to financial constraints. Most participants (17 of 24) reported acquiring HIV perinatally, two reported infection through sexual abuse and five did not indicate the mode of acquisition. Most of the participants had been taking ART for several years. Many of the participants described Christian religion as being important in their lives. Eleven of the participants were cared for by their parent; 13 of the participants had another family member as their main caregiver. Although participants were selected from both middle- and low-income backgrounds, stratified analysis by socio-economic background showed similarities in experiences of restrictions and messaging between the two groups.

3.2 | Experiences of restrictions

Participants were not asked directly about experiences of restrictions and messaging. However, participants reported high levels of parental and familial surveillance, which they linked to their age, gender and HIV status. They described being told repeatedly how they should or should not act by parents, guardians, healthcare providers and less frequently by their peers. These messages focused on three key 'don'ts': *don't* disclose your HIV status; *don't* have sex; *don't* miss your treatment.

3.3 | Don't disclose your HIV status

All the participants had extremely limited disclosure networks (Figure 1), with almost half having never themselves disclosed to any member of their family or non-family network. Participants' parents or guardians had mostly disclosed the participants' status on their behalf, with participants often excluded from the decision-making of who to tell and how. The participants' parents discouraged their children from disclosing their status to others, including other family members. Many of the participants stated that the reason why they did not disclose their status was because their parents or guardians had forbidden them from telling other people about their status: *"I want to tell my father's family: they don't know I take ART. But whenever I want to tell my father's family, my mother tells me not to tell them"* (18-year-old girl, workshop).

Parents and guardians discouraged disclosure in order to avoid anticipated stigma not only for their children but also for their families, and themselves. This was particularly in the context of perinatal infection, where the adolescent's disclosure could also be disclosure of the mother's or father's own status. When asked about where they would want to get support around disclosure, the participants largely said from the clinic, as their parents so strongly discouraged disclosure:

Mum warned me about telling them, so I think maybe someone at the clinic could help me out...I need to talk to mum, mum needs to understand that I need some kind of comfort from them. (15-year-old girl, IDI)

The restrictions on disclosure set by parents and guardians conflicted with healthcare providers' encouragement to disclose to partners in order to prevent transmission of HIV. These messages, mixed with the participants' concerns of anticipated stigma if their status was known more widely based on their perceptions of how people living with HIV are treated by others, often left participants confused and anxious around disclosure. Disclosure to boyfriends was particularly feared: *"If it were to end and then he would start telling people"* (15-year-old girl, IDI).

When a limited number of participants did disclose more widely, in some cases this led to stigma. One participant who reported disclosing more widely later changed schools on account of stigma (e.g. taunting, name-calling) she experienced from peers who found out her HIV status. The fear of unintentional disclosure also sometimes interfered with medication adherence.

Yes that was after I went into boarding grade 10, term one: I had stopped taking my medicines because I was scared that people would see and all. So when I got back home, that is when I had complications. The doctor said your medicine is not working so you go on the second line. (17-year-old)

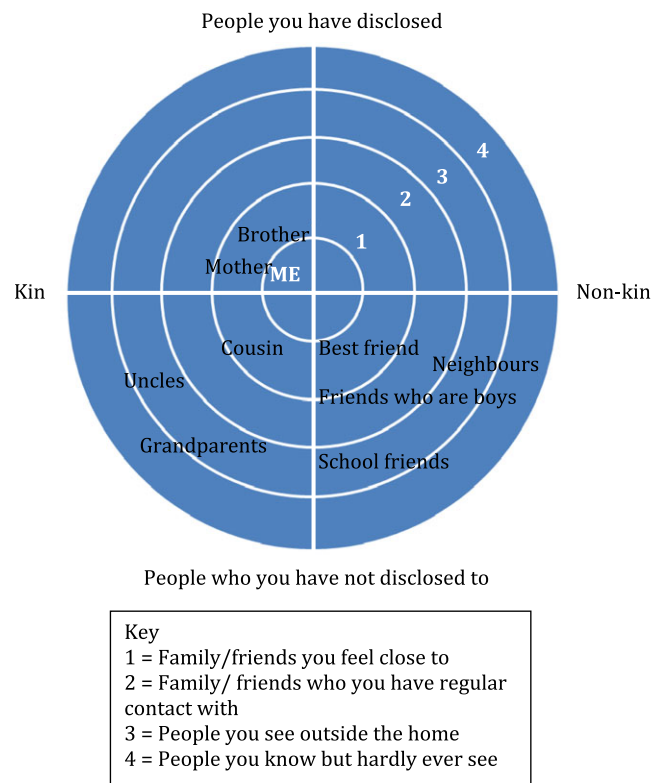


Figure 1. Affective network diagram for a 15-year-old girl living with HIV showing the family and non-family members who had and had not been disclosed to.

3.4 | Don't have sex

Participants reported being very strongly discouraged from having sex or boyfriends, not only by their parents or caregivers but also by healthcare providers at the clinic, and sometimes also their HIV-positive peers during workshops. *"People say when you are sick of HIV/AIDS you are not supposed to have a boyfriend."* (15-year-old girl, IDI). Healthcare providers, during consultations and at support groups at the clinic, as well as family members, discouraged sex often in relation to fears around re-infection and infecting others.

But they [Grandmother and Aunt] forbid me from having sex with men. That is what they stop me from doing. Because that man can have HIV as well and I can re-infect him and he can also re-infect me, we exchange. So you will not find me with men mostly, no. (16-year-old girl, IDI)

At the research workshops, some of the participants strongly encouraged other participants to abstain from sex, talking about avoiding peer pressure to have sex, and the

"dangers" of what can happen if you have sex: "I would encourage us all to abstain, not to use condoms." (17-year-old girl, workshop). Peers, therefore, appeared to both encourage and participate in restrictions to dissuade having sex, suggesting that they had internalized the restrictive messages they were receiving from their parents, guardians and healthcare providers, as well as abstinence messages at church. A few participants said that at the support groups held at the clinics, they discussed having healthy and safe sexual relationships. However, others said that when such topics were raised, the healthcare providers running the support group closed the conversation down, saying they should not be thinking of such things: "She [community lay worker] started saying... 'As long as

you are not married, we're not even going to talk about sex. We're not going to talk about marriage or dating.'" (17 year old, IDI). When given the opportunity to ask questions to a doctor during the research workshops, sexual relationships was overwhelmingly the most popular topic.

For most of the participants, restrictions and silence around sex created much anxiety. In describing their hopes and dreams for the future, getting married and having a family was central to the participants' aspirations: "I'm passionate about having a family in the future" (17 year old). Pictures of families were consistently depicted in the collages created by the participants during the workshops (Figure 2). During the workshops, participants often described how HIV will not stop



Figure 2. Collages created by participants during research workshops: two examples (a and b) showing family playing a central role.

them from achieving their sexual and reproductive hopes and dreams: *“Even though I am positive, there is nothing that can stop me from marrying”* (15 year old). However, the messages around abstinence and the restrictions around sex linked to fears around re-infection or infecting others conflicted with these aspirations. This led to concerns that they may never have a relationship or get married: *“I thought maybe I was never going to get married because of my status”* (15 year old). Additionally, participants described their fears around the possibility of transmission of HIV to potential partners and children.

3.5 | Don't miss your medicine

Family members and healthcare providers alike impressed the importance of adhering to medicines upon participants. Participants reported that they, along with their parents and healthcare providers had good knowledge about the importance of ART for maintenance of good health and avoiding illness and death: *“I know that I am sick and this is the medicine which can make me survive”* (15-year-old girl, IDI). Guardians and healthcare providers at the clinic were often quoted as the reasons why the participants continued taking their medicines: *“It is because my mother tells me that I shouldn't stop taking the drugs”* (16-year-old girl, IDI). Support from family and healthcare providers was reported to be valuable in reminding participants at the time they need to take their medicines, providing information about the importance of adherence and giving encouragement to sustain their treatment taking.

However, messages of adherence were sometimes conveyed using tactics of fear, such as talking about potential consequences of non-adherence, to strongly encourage the participants to adhere to their medicines:

Let me just say that I used to skip. So when I sat, then I was like: now what if I die or I get meningitis? Because Auntie [adolescent councillor at the clinic] told me that if you don't drink your medicine, you get blind and you get deaf. So I was like: ah I might start getting blind. No let me just start taking well. And I just started taking every day. (17-year-old girl, IDI)

These messages were rarely accompanied by information about how ART works and why adherence is important: treatment literacy among participants was low, and the reasons for adherence were sometimes misunderstood. Some participants complained of being told too often about the importance of adherence, and it becoming like *“a song”* that is repeated. A couple of participants complained about the support groups at the clinics focusing too heavily on adherence, at the expense of other concerns:

When we are told all the time [about adherence], it becomes boring. . . For me, when I'm told once, I think I can get it there and then. I don't need someone to remind me over and over again. (16-year-old girl, IDI)

When the participants were non-adherent, this often led to secrecy. Because adherence was so strongly impressed upon the participants, many feared to tell either their families, or

healthcare providers at the clinic, or both if they did miss their medicines, leading to secrecy and feelings of guilt:

No wonder I don't tell people at home [that I have missed my medicines]. I just wait for the time when I come here [to the clinic] so that I can tell them. Then they give me advice on what to do. (15-year-old girl, IDI)

Reasons for non-adherence were often practical, and related to the inability to take their medicines secretly at the time they need to take their medicine: *“I usually have difficulties taking my medicines at 18 hours because I'm usually in class, when I go for tuitions”*. Despite this, both minor and major non-adherence were kept secret. Family members or healthcare professionals discovered about non-adherence only when participants' health was severely affected.

4 | DISCUSSION

Based on qualitative research, we highlight how restrictive messages emerged as key to influencing the experiences of adolescent girls living with HIV in Lusaka, Zambia. Our results identified three common restrictions communicated by families, healthcare providers and sometimes peers that can impede adolescent girls living with HIV from making informed choices about disclosure, sexual relationships and treatment. These messages were: *don't* disclose your status; *don't* have sex; and *don't* miss your medicine. Participants responded to these messages in several ways, including internalizing them, modifying their behaviour, resisting them or becoming anxious and silent.

The complex factors involved in decision-making to disclose one's HIV status in Zambia have been previously described [31,32]. Additional to these factors, we highlight that restrictions from parents and guardians around disclosure, in part to protect themselves as well as their family, particularly their mothers, from anticipated stigma, weighs heavily on their disclosure decisions. This is particularly important because HIV is often interlinked with family networks [18,19]: most ALHIV live in households with another person also living with HIV, often their parent [33]. We also highlight that in some cases, deviating from the normative script and breaking the restriction on disclosure endorsed by parents and guardians led to experienced stigma (in the case of the participant changing schools because of taunting and name calling). This highlights the conundrum adolescent girls living with HIV face as they decide whether to disclose and whose advice to listen to, parents, guardians or healthcare providers.

The emphasis placed on abstinence for young people, and particularly adolescent girls living with HIV, supports previous findings. Countries with strong conservative, Christian influence, including Zambia, have narratives of 'religiously infused moralizing', parallel to the 'ABC' prevention messages that have remained prevalent since the beginning of the HIV epidemic [34,35]. This messaging for ALHIV to 'control their sexuality' through abstinence is often disconnected from other HIV prevention strategies. Providing limited sexual and reproductive health options particularly for ALHIV, can lead to adolescents feeling unprepared for sexual experiences, and can run the risk of stigmatizing those adolescents who do not remain abstinent [35-37]. These restrictions appear in

stark contrast to the global rhetoric of possibility, opportunity and autonomy that dominate global discourse around HIV, particularly in light of treatment as prevention [38]. Rather than opportunity, and despite advances in HIV prevention including treatment as prevention [39], adolescent girls living with HIV have a tangible fear of infecting a partner or child, to the extent that they feel they may not fulfil their aspirations of having a family. Engagement with healthcare providers, parents and guardians is needed to provide age-appropriate sexual and reproductive health information that situates abstinence within other prevention options for ALHIV to choose from [35,40].

Several participants in this study reported issues with adherence, despite having adequate information and a strong desire to adhere, supporting findings from previous studies that have shown that information is necessary but not sufficient to ensure good adherence over time [41]. Restrictions that assign moral responsibility and instil fear may inadvertently dismiss the social challenges that adolescents face in adhering, and encourage silence around non-adherence [42-44]. Adherence support provided by family members and healthcare providers should therefore recognize the broader social and environmental challenges of adherence for ALHIV, acknowledging a margin of flexibility for adherence, and understanding the fluidity of adherence as they grow up with HIV [45]. Such support could provide a more enabling environment for adherence, rather than one inadvertently encouraging resistance or secrecy.

Our research is limited in several ways. Firstly, we were not able to collect data from parents, guardians or health care providers, so our analysis is based only on the perspectives of the adolescent girls who participated. Future research with these stakeholders could shed light on how and why they communicate in the way they do and how to foster supportive and empowering relationships and communication. Secondly, we were not able to include adolescent boys living with HIV in the study and thus could not directly explore whether restrictive messaging differs by gender. In addition, our study did not include adolescent girls not living with HIV, which provides challenges in understanding whether the messaging, especially around sex, differs for adolescent girls with unknown or negative HIV status. Lastly, due to the qualitative nature of the study and the small sample size, we were not able to fully explore how restrictive messaging may have varied among adolescent girls living with HIV by various characteristics, including socio-economic status, type of guardianship or mode of HIV infection. While our findings did not suggest major differences by these characteristics among our study participants, future studies with larger samples are needed to fully examine these relationships. Despite these limitations, our study provides important information on the experiences and needs of adolescent girls living with HIV in urban Zambia and suggests key areas for further research and intervention development and testing.

Parents, guardians and extended family members are crucial in the decisions that adolescents make around their health and HIV [23,24,46-48]. Providing balanced and complete information empowers adolescents to make informed and supported choices. While messages that singularly provide restrictions laden with moral responsibility can impact the view of

the self, with feelings of guilt, blame and resistance to messages [25,49]. Family-based interventions in households with ALHIV, like those being tested by Denison et al. in the Copperbelt region of Zambia [32], may help to support parent-child communication to help ALHIV to imagine and fulfil their sexual and reproductive health aspirations [50]. Determining the best combination of interventions to fully support the needs of ALHIV in a comprehensive manner requires further research.

5 | CONCLUSIONS

This research has described some of the restrictions placed on adolescent girls living with HIV and the impact this had on their experiences. Policies aiming to support adolescent girls living with HIV need to take into account these restrictions and how they are communicated, internalized or resisted by the adolescents they are meant to protect from stigma and harm. Programmes should focus on working together with parents, guardians and healthcare providers to develop supportive relationships where messages can be delivered to ALHIV in an open way that provides options and optimal support for achieving a healthy transition to adulthood and fulfilling their goals for starting safe and healthy families of their own.

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COMPETING INTERESTS

None of the authors have any conflict of interest that might conflict with this research.

AUTHORS' CONTRIBUTIONS

VB and AS were co-Principal Investigators on the study, and led the design of the study. CMY, VB, KK, SC, CC and MC all conducted data collection, and together with KS and AS were all involved in data analysis. CMY led on writing the paper, together with VB and AW. All authors commented on the paper and approved the final version.

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