



Perspectives on Self-Disclosure of HIV Status among HIV-Infected Adolescents in Harare, Zimbabwe: A Qualitative Study

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Accepted: 6 June 2023 / Published online: 22 June 2023
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Abstract

HIV self-disclosure is an important challenge affecting the physical and psychological health of adolescents living with HIV. The study's aim was to explore the perspectives of HIV-infected adolescents on self-disclosure. Using purposive sampling, 20 adolescents aged 12–19 years were recruited from a HIV care clinic at a tertiary hospital in Harare, Zimbabwe. All were vertically-infected with HIV (HIV transmitted from mother). In depth interviews were conducted to determine participants' views and experiences of self-disclosure. Interviews were analysed using the framework approach to identify main codes and themes relating to self-disclosure. Adolescents identified stigma and discrimination from peers, as well as lack of HIV knowledge as important barriers to status disclosure. They suggested that community resources such as support groups, media and religion assist them in the disclosure process. HIV status self-disclosure is a challenging task for adolescents, which is affected by individual, interpersonal and social factors. These must be borne in mind to assist with disclosure and facilitate the wellbeing of HIV-positive adolescents.

Keywords HIV · Adolescence · Self-disclosure · Qualitative · Zimbabwe

Highlights

- The study's aim was to explore the perspectives of adolescents vertically infected with HIV on self-disclosure in Harare.
- This is the first study to explore the perspectives of HIV-infected adolescents in Zimbabwe.
- Adolescents identified stigma, discrimination, and lack of HIV knowledge from peers as important barriers to disclosure.
- Despite their young age, adolescents are capable of making their own decisions about self-disclosure.
- They suggested that community resources such as support groups, media and religion assist them in the disclosure process.

The commitment worldwide to improving services and access to antiretroviral therapy (ART) has improved the survival of HIV positive children into adolescence and adulthood significantly (Berti et al., 2015). Yet, new infections occurring in this age group have resulted in an increase in the overall number of HIV infected adolescent

population (Slogrove et al., 2017). HIV transmission can be vertical or horizontal: while vertical transmission refers to HIV being transmitted from mothers to their offspring, horizontal transmission occurs when the virus is transmitted among individuals of the same generation (Myburgh et al., 2020). According to the latest UNICEF estimates, 1.6 million adolescents (10- to 19-year olds) live with HIV (UNAIDS, 2019) and approximately 84% of them reside in Sub-Saharan Africa (Slogrove & Sohn, 2018).

Adolescents have now been included on the Global Health Strategy alongside women and children, acknowledging their importance as a unique group (Every Woman Every Child, 2015). In addition to navigating the typical challenges of adolescence, both vertically and horizontally-infected adolescents are faced with fluctuating physical and psychological health, chronic use of medication, stigma and

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difficult social situations; all difficulties linked with suffering from a chronic disease (Slogrove & Sohn, 2018). However, vertically-infected adolescents often live with more advanced stages of disease and are at increased risk of treatment failure and mortality (Judd et al., 2017). Access or adherence to antiretroviral treatment (ART), retention in care, and insufficient psychosocial and reproductive health services are also important challenges for this particular group (Armstrong et al., 2018). These factors are also associated with HIV self-disclosure, defined here as the autonomous revelation of one's HIV status to family, friends, partners or other members of society (Adejumo, 2011).

The importance of adolescents disclosing to others, and the need to support them in deciding if, when, how and to whom to disclose, was acknowledged by the World Health Organization (WHO) (World Health Organization, 2013). Evidence suggests that HIV self-disclosure is associated with improved drug adherence (Stirratt et al., 2006), social support (Shacham et al., 2012), and better physical health (Calabrese et al., 2012). Non-disclosure can lead to isolation, lack of social support and depression, and can lead to mental health problems (Khan et al., 2013; Lam et al., 2007). A systematic review of self-disclosure among HIV-positive adolescents reported mixed findings, however: in some instances, self-disclosure was associated with increased social self-competence, feelings of relief and increased condom use; in other instances, self-disclosure led to heightened anxiety and stress, depressive symptoms and withdrawal (Gabbidon et al., 2020).

Not all adolescents living with HIV disclose their status. Overall disclosure rates among youths range from 97% in the United States to as low as 52% in Thailand (Lam et al., 2007; Rongkavilit et al., 2010). Evidence suggests that adolescents are not comfortable disclosing to others (Hogwood et al., 2013; Mburu et al., 2014), but will eventually disclose to family, friends, romantic partners or teachers when they feel it is 'inevitable' (Michaud et al., 2009; Wiener & Battles, 2006). Extensive research has focused on identifying barriers to disclosure, and key factors preventing adolescents from disclosing their status to others include lack of communication skill and self-efficacy, lack of normalisation, fear of rejection or abandonment by peers and romantic partners, fear of isolation, as well as concerns about psychological impact on family members (Gabbidon et al., 2020; Greeff et al., 2008; Hogwood et al., 2013). Stigma and discrimination are also major barriers for disclosure (Medley et al., 2004), including among vertically-infected individuals (Bicego et al., 2003). Conversely, evidence indicates that adolescents are more likely to disclose to others, especially to people they trust and know for longer, when adolescents are older, have known about their HIV status for longer and when they have had positive

experiences when their own status was disclosed to them (Fair & Albright, 2012).

A minority of studies on self-disclosure among HIV-infected youths have taken place in Sub-Saharan Africa, such as in Zambia, Uganda, Kenya, and South Africa (Mburu et al., 2014; Nöstlinger et al., 2015; Siu et al., 2012; Wolf et al., 2016). To our knowledge, no work has been done in Zimbabwe and specifically among adolescents. Yet, such evidence would help better understand the perspectives of HIV-infected adolescents about self-disclosure, may guide healthcare professionals to work collaboratively with adolescents to address barriers to disclose and improve health and social outcomes. For this reason, we aimed to answer the following research questions, i) What are the general views of HIV-infected adolescents on HIV status self-disclosure? ii) What are the experiences of HIV status disclosure? iii) What are the perceived barriers and facilitators to HIV self-disclosure among adolescents living in Zimbabwe?

Methods

Design

A descriptive qualitative design using in-depth interviews was used to gain insight into adolescents' perceptions and experiences of self-disclosure, a suitable method to explore deep understanding of sensitive issues (Burns et al., 2011).

Setting

This study was conducted at a HIV care weekly clinic at Harare Central Hospital, one of the two largest tertiary care hospitals in Zimbabwe, where approximately 600 HIV-infected adolescents receive care, before transitioning to an adult care. The HIV clinic serves primarily adolescents, the majority of which are vertically infected. There are no dedicated adolescent support groups available at the hospital, however patients are informed of, and can attend, support groups organised by Zvandiri programme, run by Africaid. It is clinic policy that adolescents should have a full knowledge of their HIV status by the age of 12 years.

Participants

Patients attending the clinic who were between the ages of 12 and 19 years old, who had known about their HIV status for at least six months and were able to provide informed consent or assent were eligible for the study. Their inclusion in the study did not depend on whether they had already disclosed to others, nor whether they were taking medication. Minors whose guardian did not also provide consent

were not eligible. Finally, patients who were acutely ill or who required hospitalisation were excluded from the study.

Recruitment

HIV-infected adolescents attended the clinic for comprehensive physical health reviews on Tuesdays. The frequency of these comprehensive physical health reviews varied depending upon the physical state of the young person and ranged from 3–6 months or longer for stable adolescents. On the remaining days, adolescents attended the clinic solely to collect medication or for pre-identified medical tests such as blood tests.

Recruitment for this study occurred on Tuesday morning. The researcher identified potential participants through the daily register. Effort was made to purposely sample an equal presentation of ages and gender. To ensure representation for age and gender, Participants identified for recruitment were approached to determine eligibility and interest in study participation. Adolescents who were 18 years old or over were asked to sign the informed consent form. An information sheet and consent were provided to adolescents under 18 years of age to be taken home and signed by their guardians. These were available in the local language (Shona) and in English. With guardian consent the adolescents returned to clinic for enrolment.

A final sample of 20 HIV-infected adolescents were recruited from August to November 2014 until the point of saturation. The participants' demographic characteristics are presented in Table 1. The sample was relatively balanced

across gender, with 11 boys and 9 girls interviewed. All were attending school. Seven were double orphans (both parents were deceased), ten were single orphans and three had both parents alive. Nine lived with one parent, ten lived with other relatives and one lived alone.

Procedures

Interviews were conducted on the day of recruitment or later if consent from the legal guardian was required. Each semi-structured in-depth interview lasted approximately 45 to 60 min and took place in a private room in the clinic dedicated to the study. The interviews were audio-recorded and conducted either in English or in Shona, depending on the preference of the participant, and conducted by the principal investigator, an English-speaking psychiatrist, or a qualified bilingual social scientist research assistant. Both had experience in HIV research. All participants were given 3 USD as a token of appreciation for their time. Participants (and guardians, where necessary) were also reimbursed for travel expenses if they were to return to the clinic at a later date for the interview. Ethical approval for this study was obtained from the Joint Research Committee of Harare Central Hospital, Medical and Research Council of Zimbabwe (B/679) and Human Research Ethics Committee of the University of Cape Town (HREC REF 268/2014).

Measures

A demographic questionnaire was administered at the start of each interview. An interview schedule was developed from themes arising from a literature search and after consultation with stakeholders (e.g., HIV care physicians, nurses and counsellors) that included open-ended questions on adolescents' views about self-disclosure, their disclosure experience, and perceived barriers and facilitators of disclosure (see Table 2). To explore emotions and feelings emotions maps were used. These were designed by a local artist, which show a range of different emotions (e.g., sadness, happiness, confusion, anger and anxiety). These pictures have been used among HIV-infected children aged 11 to 13 years participating in the ARROW study in Zimbabwe, and were helpful to explore adolescents' feelings (Mupambireyi, 2016). The guide was piloted on two participants and the weaknesses identified were corrected in the final interview guide, which was translated into Shona and back translated to English to ensure validity.

Analysis

All interviews were transcribed verbatim. Transcripts of interviews conducted in Shona were then translated in English by a bilingual speaker from the Linguistics

Table 1 Characteristics of study participants

	<i>N</i>	%
Demographic characteristics		
Gender		
Female	9	45
Male	11	55
Age		
12–13	3	15
14–15	6	30
16–17	5	25
18–19	6	30
Current school attendance	20	100
Parental status		
Double orphan	7	35
Single orphan	10	50
Both parents are alive	3	15
Currently living with		
One parent	9	45
Other relatives	10	50
Other	1	5

Table 2 Interview schedule

Overall theme	Key question
Knowledge about HIV	Please could you tell me about what you know about how people get HIV? Where did you learn about these different ways? Can you tell us about your experience of getting HIV? How did you feel when you came to know about HIV? How long ago was that? How do you feel now?
Adolescents' views about self-disclosure	Please could you tell me how you feel about disclosing your status to others? Could you please tell me what your family, counsellors and support group say about disclosing to others? If your friend asked you whether he/she should disclose to someone else, what will you say to him/her Health workers want to learn how they can help adolescents with this issue of disclosure. What would your message be to them?
Disclosure experience	Could you tell me about your own experience about disclosing your status to other people?

Department of the University of Zimbabwe. Each participant was given a unique identification code and all the identifying information was removed. English transcripts were then exported to NVivo 10.0 for qualitative data analysis. Demographic information was captured using Microsoft Excel. The qualitative data analysis for this study was conducted using the framework approach, involving familiarisation, identifying a thematic framework, indexing, charting, mapping and interpreting (Gale et al., 2013). After transcripts and additional information on expressions and body gestures were read thoroughly, transcripts were read again line by line for emergent themes and coded accordingly. A second researcher (KS) independently coded 3 interviews to ensure the validity of the categories, after which codes were compared and final codes agreed upon. Subsequently, these codes were used as a framework to code the remaining transcripts.

Results

Most of the participants admitted to being infected vertically. Of the 20 participants, 10 reported already having disclosed their status to at least one other person, and that between the ages of 4 to 14 years. Themes that emerged from the analysis are categorised into 3 main headings according to the research questions. These are discussed in more detail below.

General Views about HIV Status Disclosure

Participants' general views about HIV status disclosure were first explored, and it was clear that it was a difficult process for most of the participants. Some were unwilling to disclose and highlighted that; 'it is not necessary' to disclose and 'you just have to keep it a secret' and 'it's none of other [people's] business'. By not disclosing, some of these

participants reported to have faced difficult situations, such as having to explain school absenteeism due to clinic reviews or acute illnesses or explain the reasons for taking medications. This led them to make excuses or 'lie' resulting in the feeling of guilt. Those who were considering disclosing their status, emphasised on being selective with whom to disclose. One young person who had disclosed to her family talked about disclosure:

"You can tell your relatives, instead of just disclosing to anyone in the neighbourhood. Because if you do so, they can go around telling others." (Female, Age 15).

Generally, participants seemed more willing to disclose to family, followed by friends and were most reluctant to disclose to the romantic partners. As a result, some either avoid romantic relationships altogether or engaged in romantic relationships without disclosing their status. However, non-disclosure in relationships, led them to feel guilty and they talked about avoiding sex.

Experiences of Disclosure

The second research question focused on exploring the experiences of ten participants whose status were known to others. Their disclosures were divided into third party, accidental and active disclosures.

Third party disclosure tended to occur when family, friends or professionals disclosed the participants' diagnosis to others. Although in some instances adolescents described how their status was disclosed by health professionals to their relatives when they visited the hospital due to an acute illness, most third-party disclosures were reported to be from a family member. According to participants, situations which led to disclosure by their parents included: parents arranging for their care with other relatives in case of parental severe illnesses or when parents, due to their work

commitments, required assistance from others to supervise their medication intake. Moreover, when parents were not alive and other relatives had to take care of them, third party disclosure occurred to share care and responsibility. One participant described that his mother told her siblings about his status when she became ill by saying:

‘I was tested... maybe soon I will be dead. You guys look after my son. He takes pills.’ (Male, Age 17).

Most participants were not asked for their consent before this disclosure happened. Some of the participants whose status was disclosed by third party had negative experience for example this young person experienced discrimination by her stepmother:

“She (step-mother) never wanted my pants to mix with hers or her children. She would say I would spread HIV to her children. She burnt all my pants that were at home saying that I will infect her children with HIV.” (Female, Age 14).

Most reports of accidental disclosure among participants occurred when other saw them with antiretroviral drugs. One adolescent experienced a similar situation where she was surprised by her aunt when she said:

“I know you’re HIV+ because you’re taking these drugs.” (Female, Age 18).

Some participants admitted to making a conscious choice and actively disclosing to others. Participants described different circumstances that led them to disclose to others. Disclosure to family members, outside the parent-sibling unit, seemed to occur primarily among participants who were orphaned and had to live with other family members. This was to ensure that adults were aware of their health and medication needs. Decision to tell friends was not easy and in some instances, friends prompted disclosure through trust and non-judgmental attitudes towards people. Many adolescents in the study reported thinking and observing their friends for a long time before actual disclosure. In some cases, they disclosed when their friends convinced them by showing their understanding and compassion towards people living with HIV as elicited by the following quote:

You will see the way he will speak like if you say, ‘That person is HIV positive and I want to play with her,’ – you will see how he responds. (If he says) ‘You don’t laugh at her; you don’t know maybe she got HIV through birth or maybe she got HIV through her breastfeeding mother.’ (But) if he responds and says, ‘Don’t play with her; you will get HIV also’, you will

know that you must not tell this person. (Female, age 16).

Nearly all participants who actively disclosed to family and friends on their own terms had a good experience, positive response and felt supported. Despite many feeling nervous and worried about disclosing, reports of feeling supported and loved were highlighted. These experiences are depicted by the following quotes:

“When I told him (my brother) the truth, I thought that he would just say, ‘You are no longer my brother now,’ but he loves me more than he did”. (Male, age 13).

“You’re still my friend as it is; HIV is just a disease, it doesn’t take friendship away”. (Female, age 18).

“It’s more like support for you because they (relatives) remind you of your tablets and you don’t have to hide”. (Male, age 17).

On the other hand, some participants described how the decision to disclose to their romantic partners was particularly challenging. Concerns about losing them and the potential for third party disclosure was a real threat. For the few participants who had disclosed their HIV status to their partners, the outcomes varied. One had a positive response; however, the other was rejected by her boyfriend. These experiences are highlighted in the following quotations:

“One of the days he just looked me in my eyes and said, ‘Why do your eyes have tears?’ and I said, ‘Nothing.’ Then he asked again, and I said nothing and he said, ‘You have something you want to tell me but you don’t want to say it; I want to know.’ Then I told him at that moment, and he took it the easy way and said, ‘It’s OK; it happened,’ and he said, ‘Are we able to go and get tested?’” (Female, Age 19).

‘We are no longer lovers, don’t ever call me’ then I asked him ‘why?’ (And he said,) ‘Don’t ever ask me, just have a relationship with someone who is same to you.... A person who is HIV positive, I cannot get married to (a) person who has HIV’. (Female, age 19).

Factors Associated with Disclosure

The third research question of the study was to explore the barriers and facilitators to HIV self-disclosure. Participants

acknowledged that the decision to disclose their HIV status to others was difficult, and this was hindered or facilitated by several factors. Family influence varied for different individuals. Some felt family was helpful in deciding who and when to disclose their HIV status to. Others reported that their family inhibited their decision to disclose, by conveying their preference for their status to remain a secret or by the subtle threat of the trouble they might get into, if they do disclose without parental consent. Other barriers and facilitators are described below.

Barriers to Status Disclosure

Three types of barriers to status disclosure were identified: i) misconceptions about HIV, ii) fear of breach of confidentiality, and iii) fear of rejection.

Misconceptions about HIV with Associated Stigma and Discrimination

A few participants highlighted lack of knowledge and misconception about HIV in the general population as a barrier to disclosure. One participant mentioned being scared to disclose as she heard her class fellows talking about HIV in a negative manner:

“Ahh people with HIV are very sick and they don’t have a long time to live, they’ll die soon”. (Female, 18 years).

Some participants also showed concerns that the general population do not always make the distinction between HIV and AIDS. The term being “HIV positive” is then equated to a “death sentence” or “totally dead” as explained by an 18-year-old about her class fellows:

“Some can say, people living with HIV are about to die. Because they (school fellows) don’t understand, they think HIV is like death and people are sick. (We should make them understand by) telling them what HIV and the difference between HIV and AIDS is”. (Female, age 18).

One participant was concerned that they may be perceived as promiscuous if they disclosed their status, leading the young person to pre-empt such assumption and feeling the need to explain to her boyfriend:

“I want to tell him (boyfriend) that my mother is the one who gave me HIV and I was born with HIV... that’s all”. (Female, age 16).

Another participant mentioned lack of knowledge of the public, leading to known HIV infected people being discriminated against, for example, being given different utensils to eat with. She had quite a similar experience with her aunt, who used to tell her:

“Don’t touch this, don’t do that. If you touch the thing, she said not to touch ‘hoooo, you will be in trouble, the day will turn bad. I think she (my aunt) thought that I could transmit the HIV virus through touching things.” (Female, Age 19).

Fear of Breach of Confidentiality

Fear of breach of confidentiality or third-party disclosure was highlighted by many as a major concern. Intentional, sometimes malicious, disclosure by third parties was reported by several participants, as expressed in the following quotes:

“Look at her, this is what she is”. (Female, age 16).

“If you tell them (teachers) what you are, they (school) can give you as an example at the Assembly”. (Female, age 19).

Rejection

Many young people expressed worries about rejection after disclosure; this was partly linked to witnessing how other young persons were being treated after disclosing their status. One young person mentioned that his school friends denigrate people with HIV, and this made him worried as depicted by the following quote:

“I feel that one day when they realise that I have HIV, they won’t even greet me.” (Male, age 17).

Some experience discrimination even when their HIV status were not known, as they were suspected of having HIV due to characteristic physical appearance linked with HIV and/or association with someone with HIV.

“I don’t have friends. The one that I have, if I go to play with her, she just ‘scratches’ me and goes to play with others. If I go to her, she says ‘Your sister died of HIV, and I don’t know if you have HIV too”. (Female, age 16).

In summary, an interplay of the lack of knowledge from family, peers, and teachers, as well as stigma and discrimination prevented self-disclosure of HIV status to others.

Facilitators of Status Disclosure

Several individual, interpersonal, and social factors were found to facilitate status disclosure.

Individual Factors

Participants described future circumstances where they felt they would be better placed to self-disclose. Some felt this would be when they were older, employed, or self-sufficient, or when they have acquired better communication skills:

“I will tell others when the time will be right, around age 19 years, because I will know how to say it”. (Female, age 16).

“I will call you [my friends], I would say come and hear the story here, then I will say I have this and that disease. I have HIV and if they don’t want to play with me, I can take care of myself because I will be working”. (Male, age 14).

Some felt the desire to be honest and gain a closer relationship with friends, as exemplified by the following quote:

One participant said that not disclosing to his friend makes him feel like: ‘I am not able to be (a friend just as I should be to him) [an honest friend]’. (Male, age 17).

Interpersonal Factors

The characteristics of the person participants were considering disclosing to were also an important factor. These characteristics included the nature of the relationship with the other person, the length of time they had known the person for, the qualities of the person, and that person’s HIV status.; These considerations are expressed by two participants in the following quotes:

“The character of a person depends on being reliable and understanding and reading the Bible. The thing I consider when choosing a person is the attitude. If a person has an ‘attitude of gossiping’ that person is

not good. The other person who is quiet and keeps secrets, you can tell him.” (Male, age 14).

“I will say you can disclose to [a] person you trust and must be a very good friend. I will say wait a bit in disclosing until you have given yourself time to learn more about your friend, is she not going to disclose the information to others at home [without permission]”. (Female, age 15).

Social Factors

Social factors, such as improved HIV related knowledge, support groups, support from health professionals, religious leaders and media were seen to facilitate disclosure among participants. One participant expressed the need to improve community knowledge about HIV to improve hope and facilitate disclosure:

“I want to tell other people that your HIV positive status does not mean that you are dead. You have many years to live. Any HIV positive person has an advantage to a person does not know their HIV status”. (Female, age 18).

The availability of support groups and health workers were noted as important facilitators of status disclosure. Several participants reported receiving useful advice from doctors and counsellors, relating to when or whom to disclose to, and the benefits of disclosure, such as reminders to take medication and for clinic reviews, as well as benefits of safe intercourse as depicted by the following advice given by the clinical staff:

“You can tell some people because it makes it free for you to take your tablets anywhere because everyone knows” (Female, age 18).

Other participants felt that support groups were an important resource to help them discuss disclosure and advising ways on how to select the right people to disclose to, such as illustrated in the following quote:

“Yes, they [support group] advise. They advise that we should be free or comfortable, [as] being HIV does not mean that you are isolated. They say that tell someone who is ‘open’ to you. Who is concerned about you”. (Male, age 19).

Support from religious leaders was mentioned by a few participants to cope with HIV; a 14-year-old male felt that

the supportive way his pastor approached him made it easy for him to disclose:

There was a church meeting in South Africa that I missed; then they called me saying ‘Where are you? We need you here.’ Then I said, ‘No I am not at home, I am admitted at hospital.’ They said, ‘What happened?’ and I said, ‘There are some issues I am fixing,’ and then they said, ‘We are coming there.’ Then my Pastor came, and he said that, ‘We need to know what is happening to our child because when you are in my church, you are also my son,’ and I said, ‘The thing is I am HIV positive.’ He just said, ‘It is well; In God we trust. All things will work together.’ That was his response. (Male, age 14).

Furthermore, the way his pastor explained the link of illness to God helped him to disclose to more people at the church. This is shown by the following quote:

In our church we say “All things are from God, and we give praise to God for all things. So, if this is HIV, it belongs to God.” (Male, Age 14).

One participant mentioned feeling inadequate and reluctant to disclose to his friend, until he heard a big local star going public about his HIV positive status:

“It was due to advertisement on the TV (and) radio about HIV status, this comforted me, and it gave me the courage to easily tell my friend. For example, I can sit and watch Oliver Mtukudzi. He is the biggest local artist, and he is HIV positive, he can encourage people who (are) HIV positive. He advises that you must be open with your status because you’re not different to those who are HIV. We are all people”. (Male, age 19).

Discussion

The aim of this study was to explore the perspectives on HIV status self-disclosure in 12- to 19-year-old HIV-infected adolescents attending a HIV care clinic at a tertiary hospital in Harare, Zimbabwe. Results indicated that adolescents considered carefully whether to disclose or not, how to disclose, when and to whom. This suggests that, despite their young age, adolescents can make their own decisions about self-disclosure.

Adolescents were generally hesitant to self-disclose to their peers and romantic partners, which supports previous

evidence from high-income countries and Africa (Gabbidon et al., 2020). Also supporting previous studies was the fact that adolescents preferred to disclose once they felt more independent or when they felt their peers or the community would be more understanding of their status (Hogwood et al., 2013; Siu et al., 2012). Moreover, similarly to Siu et al. (2012)’s study in Uganda, many adolescents’ decision to disclose or not was done after gauging others people’s potential responses to status disclosure.

Many adolescents were fearful of disclosure due to several individual, interpersonal, and social factors, such as anticipated rejection, fear of breach of confidentiality, family influence to prevent disclosure and stigma and discrimination. These findings are confirmed in developed countries and in Africa (Gabbidon et al., 2020; Siu et al., 2012). Stigma and discrimination, and this both in the community and in schools, were the most important barriers reported, supporting other studies conducted in Sub-Saharan Africa including Zimbabwe (Campbell et al., 2010; Deacon & Stephney, 2007). Such discriminatory behaviours are often influenced by the lack of knowledge and negative attitude of parents, teachers, and society in general (Castle, 2004), and these seemed to have a direct impact on non-disclosure among adolescents in the present study. Some of the knowledge gaps identified by adolescents included limited knowledge about ways of transmission and non-transmission of HIV, and the perception that HIV transmission only occurred through sexual promiscuity. Adolescents also alluded to the fact that the community was generally unaware of the difference between HIV and AIDS and believed that HIV was equivalent to death. These findings corroborate those of other studies where adolescents felt frustrated on the discriminatory behaviours stemming from ignorance, and wished for peers to know more about HIV (Gillard & Roark, 2013; Hogwood et al., 2013).

While some researchers argue that there is more to stigma than only insufficient knowledge (Deacon & Stephney, 2007; Smith, 2013), studies assessing HIV stigma-reduction interventions suggest that improving HIV knowledge does result in stigma reduction. This was the case in two interventional studies conducted in schools involving training school teachers or school children about various aspects of HIV (Chao et al., 2010; Klepp et al., 1994). In another study conducted in a school in rural China, knowledge about non-transmission of HIV was a key aspect of HIV education which was strongly associated with stigma reduction (Qin et al., 2013). These findings have important public health implications for the prevention of stigma, which in turn could facilitate HIV self-disclosure. Education on HIV/AIDS has already been included in the curriculum of primary and secondary schools in Zimbabwe since 2006 (UNAIDS, 2008). However, given the study’s

findings, to reduce stigma, there clearly is a need to revise the curriculum to emphasise information on the ways of non-transmission of HIV and on the difference between HIV and AIDS, and a need to also target parents and teachers at school.

Previous studies conducted among HIV-infected adolescents have explored the importance of support groups in decreasing feelings of isolation and in improving perceived support (Hogwood et al., 2013). However, the role of support groups during the self-disclosure process had not yet been explored among adolescents. The present study found that, despite only few adolescents admitting to having attended support groups, those who did generally described attendance as a positive experience. Overall, healthcare providers were seen as helpful and supportive and adolescents expressed a wish for increased support from healthcare providers to help them decide about who to disclose to, how to disclose and how to deal with the psychological impact after self-disclosure. In Zimbabwe, there are well-established community-based peer counsellors and psychosocial support groups in place, such as ‘Zvandiri’ and ‘Champions for life’. The Zvandiri programme provides support on disclosure, including the legal and ethical implications of non-disclosure to sexual partners, skills to disclose to others and post disclosure counselling. Early evidence suggests the positive impact of Zvandiri program in supporting HIV-infected adolescents and this program has now been taken up by the Government of Zimbabwe (Mavhu et al., 2013). Furthermore, there is an ongoing cluster randomised controlled trial assessing the effectiveness of Zvandiri program on adherence and retention in care, both of which are facilitated by disclosure (Mavhu et al., 2017). Unfortunately, none of the participants in this study attended this support group, which raises a question of acceptability or accessibility of such support services in this population. Though not reported in the present paper, participants’ views and practices about HIV self-disclosure seemed to be influenced by the type of support they received after their status was disclosed to them. Interventions or support groups may therefore also need to target mothers who are HIV positive, before they disclose to their HIV positive child.

Furthermore, in the present study, famous local stars disclosing their HIV status publicly was considered a motivating factor to self-disclose. Mass media was explored as a resource to reduce stigma in Botswana, through a television drama (O’Leary et al., 2007), and in Malawi, through a programme called ‘Radio Diaries’, which featured HIV-infected people telling their life stories (Creel et al., 2011). Both programmes resulted in a decreased level of stigma, especially among younger participants, but had no effect on perceived disclosure practices.

Finally, religious leaders were mentioned as an influential factor in HIV status disclosure, in decreasing social isolation

and providing support. Further exploration of this finding is required, however, since some adolescents also explained that, according to their religion, HIV was not a disease but an ‘evil spirit’ which could not be cured by medication but by spiritual powers (results not presented here). There are examples of religion bringing dramatic changes in people’s lives, such as in Senegal, where HIV prevalence fell dramatically when introduced HIV prevention programmes which combined religious beliefs with media (UNAIDS, 1999). Therefore, more research employing longitudinal designs are needed to explore ways in which media and religion could be used effectively as a facilitator to disclosure.

A few limitations of this study should be considered while interpreting these findings. First, some of the interviews were conducted in the local language and were translated to English, which could have resulted in some interpretation errors. Secondly data collection was not triangulated, which would have provided more in-depth information and insight into HIV status disclosure. Despite these limitations, by recruiting participants from tertiary care we were able to collect data from a wider variety of participants. At the time of this study, most HIV infected adolescents were being treated at tertiary care level. And the process of transferring those who were stable to primary care had just started.

Conclusions

Despite these limitations, this study is the first in Zimbabwe to investigate the perspectives of HIV-infected adolescents in the process of self-disclosure. Overall, our findings indicate that adolescents find disclosing their HIV status to peers and romantic partners challenging. Disclosure is hindered by lack or limited knowledge about HIV, which worsen stigma and discrimination towards adolescents living with HIV, as well as by fears related to confidentiality breach or rejection. However, several factors, such as improved HIV knowledge, media and support via support groups, religious leaders, and health professionals, facilitated status disclosure. These findings have several important implications for practice, policy, and research, which ultimately could help facilitate the process of disclosure among this vulnerable population. Practical implications more specifically include the need for the national HIV/AIDS school curriculum to be updated to clarify ways of non-transmission of HIV, the difference between HIV and AIDS, and for this information to be targeted at parents and teachers too; for support groups to help adolescents with disclosing; for psychoeducation to be provided to mothers to emphasise the importance of appropriate support after disclosing to the child; and the potential role mass media has in reducing stigma.

Data availability

Data are available upon request.

Author Contributions R.K. and K.S. contributed to the study conception and design. Material preparation, data collection and analysis were performed by R.K. The first draft of the manuscript was written by E.C.G., and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

Funding This study was supported by the National Institute of Mental Health (NIMH) of the National Institutes of Health (NIH) under Award Number U19MH095699. Open access funding provided by University of Cape Town.

Compliance with Ethical Standards

Conflict of Interest The authors declare no competing interests.

Ethics Approval Ethical approval for this study was obtained from the Joint Research Committee of Harare Central Hospital, Medical and Research Council of Zimbabwe (B/679) and Human Research Ethics Committee of the University of Cape Town (HREC REF 268/2014).

Informed Consent Informed consent was obtained from all individual participants included in the study. In the case of minors, informed consent was also obtained from a legal guardian.

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