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Research Article

“Growing up and growing old with HIV”: HIV+ adolescents’ experiences of disclosing statuses to romantic partners in Bulawayo, ZimbabwePhilani Mlilo^{1*}, Cowen Dziva², Vuyisile Precious Moyo³, Nonhlanhla Lindelwe Ndondo⁴, Zanele Ndlovu¹ and Nkosinathi Muyambo⁵¹Department of Sociology and Social Anthropology, Great Zimbabwe University, Masvingo, Zimbabwe²Nehanda Centre for Gender and Cultural Studies, Great Zimbabwe University, Masvingo, Zimbabwe³Centre for Applied Social Sciences, University of Zimbabwe, Masvingo, Zimbabwe⁴Alan J Flisher School of Public Mental Health, University of Cape Town, South Africa⁵School of Religion, Philosophy and Classics, University of KwaZulu-Natal, Pietermaritzburg campus, South Africa*Correspondence: philanimliloj@gmail.com

This article explores the experiences of HIV-positive adolescents disclosing their status to romantic partners in Bulawayo, Zimbabwe. Disclosure of HIV status continues to be one of the most pressing issues facing adolescents, especially those in relationships, yet health care workers have minimal tailored guidance on how to approach this except to encourage full disclosure. Motives for disclosure were: guilty conscience; legal and ethical obligations; preventing partners being infected; and supportive people, honesty and trust. Disclosure was done on a one-on-one basis in public spaces such as roadsides where the adolescents usually met, or in health care facilities through the help of health care workers, and through mobile phones using WhatsApp. Results revealed that disclosure was associated with negative and positive outcomes ranging from disruption of relationships, depression, breaches of confidential information and, in some instances, relationship and marriage assurance. However, results clearly showed that adolescents living with HIV struggle with disclosure because the process is complex and loaded with emotions and the outcomes can be unpredictable and difficult to handle. Optimism towards treatment, social support, rationalisation, and social comparison through attributing new meanings to the disease were employed to deal with negative outcomes of disclosure. Therefore, the development and implementation of evidence-based initiatives to raise awareness and train the youth to disclose is recommended. Through their experiences, we can learn what works well and what needs to be strengthened.

Keywords: adolescence, disclosure, intimate, partner, perspective, relationship status, young persons

Introduction

The HIV and AIDS scourge has affected many people, including adolescents and the youth, worldwide. The World Health Organization estimated that 10.3 million youths aged 15–24 years were living with HIV and that half of all new infections occur among young people (Marfatia & Naswa, 2010). It is further claimed that 4 million people younger than 20 years are diagnosed with STIs including herpes, human papilloma virus (HPV), chlamydia, gonorrhoea, and the HIV (Marfatia & Naswa, 2010).

Relatedly, United Nations Programme on HIV and AIDS (UNAIDS, 2012) revealed that over 3 million children globally were estimated to be living with HIV, which is most commonly spread through vertical transmission during pregnancy, delivery, and breastfeeding. That report further revealed that 92 per cent of pregnant women with HIV were living in sub-Saharan Africa and just fewer than 60 percent were receiving antiretroviral therapy (UNAIDS, 2012). This,

therefore, explains the high number of infections occurring among adolescents. However, mother-to-child transmission can be prevented by administering antiretroviral therapy to mothers with HIV during pregnancy, delivery, and breastfeeding, and to their newborn babies (Kranzer et al, 2014).

To accentuate the above findings, in 2011 there were an estimated 330 000 new infections among adolescents, most of whom had been perinatally infected (UNAIDS, 2011) and over 90 percent of whom were living in sub-Saharan Africa (UNAIDS, 2012). Consequently, sub-Saharan Africa is the region where most children infected with HIV live (Kranzer et al, 2014).

In 2011, it was estimated that in Zimbabwe, 2.8 percent of 15-year-olds were seropositive (138 642 HIV-positive children); 13 711 were newly infected in 2010 (MoHCW, 2012 in Mavhu et al, 2013). In addition, 17 per cent of those aged 15–19 years in Zimbabwe in 2015 reported having had sex with a man ten years older in the past year (ZIMSTAT,

2015). These findings implied that adolescents were engaging in sexual activities and were therefore more at risk of contracting HIV and AIDS.

In a bid to address HIV and AIDS among adolescents, many strategies and programmes have been put in place to reduce the spread of the virus and to increase testing services for adolescents, e.g., Determined Resilient Empowered AIDS Free Mentored and Safe Girls & Women (DREAMS), voluntary medical male circumcision, and self-testing. Moreover, by 2004 antiretroviral therapy (ART) was made available to the public; by the end of 2011, 37 590 children aged 15 years were receiving ART nationwide (Mavhu et al, 2013).

Despite these initiatives, adolescents still face an array of consequences of the HIV/AIDS pandemic. As parents die, adolescents are sent to extended families for upbringing, burdened by recurrent illnesses, delayed puberty, intellectual impairment, and chronic skin disease (Ferrand, 2007). In addition, adolescents face a range of psychosocial problems such as accepting their HIV status, grief over their deceased parents, other sero-positive family members, and big question marks over future dating, disclosing to intimate partners and marriage. Thus, as they grow up, HIV+ adolescents face difficult decisions about when and how to disclose their HIV status.

The survival of HIV-positive children therefore raises challenges as they grow particularly on issues of disclosure. Many parents and guardians are even reluctant to allow children living with HIV to know their status for fear of being blamed and questioned how they became infected (Ingabire & Mutesa, 2014). Regardless of the complexity of the social challenges facing adolescents, the issue of stigma affects them more than any other group in society. This on its own is traumatic enough. It is important to find out from these adolescents what it is like to disclose one's HIV-positive status to a romantic partner.

Background

Disclosure of HIV status has been the subject of much discussion and deliberation because of the complexities associated with a process that is intensely personal and emotional. A study in Zimbabwe by Mavhu et al. (2013) showed that receiving an HIV-positive diagnosis remains one of the most difficult life events for adolescents living with HIV and AIDS. Also, WHO (2011) noted that health care workers and care givers have little guidance about disclosure tailored for adolescents except to encourage full disclosure in developmentally appropriate stages. Failure to elaborate on the stages of how disclosure should be done is cause for concern for adolescents who are in relationships — particularly since the Law Codification and Reform Act of 2013 (at Chapter 9: 23 under section 79) in Zimbabwe makes it a criminal offence for someone who knows that they are HIV-positive to transmit the virus to someone else or do anything that is likely to lead to transmission (ZIMLII, 2016).

While numerous studies have focused on adolescents in Zimbabwe, existing research (Ferrand et al., 2007; Mavhu et al., 2013; Kranzer et al., 2014; McHugh et al., 2018) has tended to focus on enhancement of psychosocial support and familial silence around HIV, while neglecting the

experiences of HIV-positive adolescents in disclosing their status to intimate partners.

As a result, adolescents have been denied a voice to express their experiences and perceptions. Against this backdrop, this study intended to fill that knowledge gap because knowing one's HIV status is recognised as an important precondition for effective adherence to antiretroviral therapy (De Baets et al, 2008; Bikaako-Kajura et al, 2006). A study of this nature feeds into policymaking through the integration of the 95-95-95 targets meant to curb new HIV infections and ensure healthy lives for all, as advocated by the 2030 Agenda for Sustainable Development. This view is supported by UNAIDS (1997), which declared that disclosure of HIV status to sexual partners is an important prevention goal emphasised by the WHO and the US Centres for Disease Control and Prevention (CDC, 2005) in their protocols for HIV testing and counselling.

In the same vein, adolescents are most vulnerable to HIV and AIDS (adolescent sex workers, sexual abuse, and sex with older people). Hence one might argue that adolescent HIV/AIDS constitutes a separate epidemic that needs to be handled and managed differently from adult HIV and is worth pursuing. Also, HIV-status disclosure to romantic partners is distinct from disclosure to younger children and therefore requires tailoring of appropriate guidelines instead of a one-size-fits-all approach. Lastly, this study reveals a microcosm of the macrocosm — the lived experiences of HIV-positive adolescents disclosing their status to romantic partners — and will contribute to the scant literature on disclosure in Zimbabwe.

Aim of the study

The study explored the experiences of HIV-positive adolescents in Luvuvu, Bulawayo, disclosing their status to their romantic partners. The aims were:

- To establish what motivated disclosure by adolescents to their partners;
- To find out how disclosure of HIV status intimate partners was done;
- To explore ways that romantic partners responded to disclosure;
- To explore the ways that HIV-positive adolescents coped after disclosure.

Literature review

Modalities for HIV disclosure

Disclosure of HIV status has been the subject of much discussion, debate and deliberation since the beginning of the epidemic. By nature, disclosing a positive HIV status is typically problematic and it is fraught with concern and fear regarding the aftermaths of the disclosure, which has some bearing on the drive to disclose (Paxton 2002). While certain psychological and social assets ameliorate the worry, disclosure remains a salient issue for people living with HIV and AIDS (Paxton, 2002). Thus, adolescents living with HIV and AIDS are principally vulnerable to the universal concerns about disclosure due to their social, psychological, and cognitive developmental stage.

In the last two decades, advances in treatments of HIV infection have led to longer life spans, improved quality of

life and fewer psychiatric problems for youth living with HIV (Donenberg, 2005). However, disclosure remains a source of major distress in the lives of adolescents and those who support them (Wiener & Battles 2006).

WHO (2004) highlights that HIV testing and counselling serves as a critical prevention and treatment tool in the control of the HIV epidemic. HIV testing and counselling programmes emphasise the importance of HIV-status disclosure by people living with HIV, particularly to their sexual partners (WHO, 2004). Disclosure remains a significant public health goal because it motivates sexual partners to seek testing, change behaviour and, ultimately, decrease transmission of HIV.

WHO further contended that disclosure has several potential benefits for individuals, including increased opportunities for social support, improved access to necessary medical care and ART, increased opportunities to discuss and implement HIV-risk reduction with partners, and increased opportunities to plan for the future (WHO, 2004). Besides these benefits, HIV-status disclosure to sexual partners also poses many risks for the individual, including loss of economic support, blame, desertion, physical and emotional abuse, discrimination, and disruption of family relationships. This outlook is supported by Eustace and Ilagan (2010) who found the process of HIV disclosure to sometimes be detrimental to an individual's well-being and peace of mind. A meta-analysis of 21 studies conducted by Smith et al. (2008) concluded that when people living with HIV felt that HIV carried a greater stigma, they reported less social support. Greater HIV stigma also corresponded with fewer disclosures of HIV status. Stigma is a major barrier to HIV disclosure.

Importance of disclosure

Disclosure is something that every person living with HIV experiences and struggles with due to the complexity of the process, diverse emotions, and unpredictable outcomes. Despite the difficulties that disclosure might pose, non-disclosure has unfavourable effects on the person living with HIV and is associated with personal distress, loneliness and social isolation (Rodkjaer et al., 2011, Chaudoir et al., 2011, Stutterheim et al., 2011). Furthermore, non-disclosure may lead to non-adherence to hide the illness from others (Arnold et al., 2008). Disclosure is not only imperative for people living with HIV, but is also vital for those around them. For example, partners/children who are unaware of their partners'/parent's HIV-status can often perceive that something is wrong and become concerned when they are unable to express their feelings (Kennedy et al., 2010, Murphy et al., 2011).

In the context of society and community, disclosure is essential for public health purposes to curtail the spread of HIV. Also, non-disclosure of one's HIV-positive status before engaging in a sexual act can lead to criminal prosecution in places such as Canada (Mitri et al., 2013). Given the personal, societal and legal importance of HIV disclosure, it is important to understand people's lived experiences of HIV disclosure, as well as effective disclosure strategies and interventions for adolescents and people living with HIV.

Disclosure to individuals within one's social network can lead to improved behaviour and health outcomes,

such as adherence (Dodds et al, 2003; Anglemeyer, 2013) and may lead to better mental well-being. Disclosure to sexual partners encourages communication and informed decision-making about sexual behaviours and risks (Dodds et al, 2003). Adolescents living with HIV may benefit from disclosure by gaining control, sharing responsibility for sexual risk with partners, and eliciting social support. This view is supported by Bird and Voisin (2011) who underscored that the social support which comes as a result of disclosure may foster coping and psychological adjustment to diagnosis.

Similarly, studies in both rural and urban settings across sub-Saharan Africa have shown disclosure of HIV-status to be associated with progressive outcomes including increased social support (Maman et al., 2003, Ogoina et al., 2015), reduced internalised stigma (Geary et al., 2014), improved mental health (King et al., 2008), and safer sexual behaviours (Rujumba et al., 2012). Other research in the region associates disclosure to sexual partners with augmented understanding and support (Medley et al., 2004; Obermeyer et al., 2011), trust (Nabukeera-Barungi et al., 2015, King et al., 2008) and HIV care uptake (Deribe et al., 2008; King et al., 2008).

While the majority of literature on disclosure is from developed countries like the USA and countries of Europe, there is a growing body of literature from sub-Saharan Africa (Vaz et al., 2008; Bikaako-Kajura et al., 2006; Kouyoumdjian et al., 2005; Vreeman et al., 2010; Vaez et al., 2011; Menon et al., 2007; Biadgilign et al., 2011). Nonetheless, a greater deal of this literature is based on care givers' and health professionals' points of view while little is written from adolescents' point of view. To sum up: it seems that levels of disclosure of children's and adolescents' HIV status remains low, despite documented positive effects of disclosure. These gaps in the literature were investigated further in our study.

Study area

This study was conducted in Bulawayo and was limited to Luveve Clinic catchment area on the western fringe of Bulawayo, bordering the high density suburbs of Emakhandeni and Lobengula.

Methodology

Study design and research approach

This study employed a qualitative, phenomenological research design to gain deeper insights into the experiences of adolescents who disclosed their HIV status to their romantic partners in Bulawayo. According to Creswell (2013), phenomenology allows the researcher to describe an individual's experience of a phenomenon as described by the participant. This description culminates in the crux of the experiences for several individuals who have all experienced the phenomenon. Therefore, phenomenology enabled the researchers to glean multiple perspectives rather than generalising from the experiences of HIV-positive adolescents disclosing the status to their partners. This is reiterated by Gillis and Jackson (2002) who observed that qualitative research emphasizes seeing the world from participants' perspectives, with the goal of understanding rather than predicting.

Study population and sampling

The study purposively targeted 15- to 19-year-old HIV-positive adolescents from different social strata who were in a relationship, aware of their HIV-status and had disclosed their status to their partners. The study sample comprised 30 subjects, 15 males and 15 females, and was partly determined by theme on one hand and partly by data saturation (a point in data collection when new data no longer bring additional insights to the research questions). Adolescents were recruited through AFRICAID Zvandiri support groups whom the researcher and the Community Adolescent Treatment Supporter (CATS) thought would best answer the research questions and meet objectives. This approach is also supported by Coyne (in Punch [2005]) who noted that cases are carefully chosen to illuminate issues pertinent to the research. Purposive sampling was used because it allowed the researcher to group participants according to preselected criteria relevant to particular research questions. Treatment supporters were roped in during the recruitment process to get the most out of participation and disclosure of sensitive issues among adolescents.

Data collection

Data was collected from June to August 2019 using a semi-structured approach facilitated by a researcher or research assistant. A semi-structured approach was adopted during the interview process, leaving room for probing and deep understanding of issues. An in-depth guide was pre-tested on five respondents to ensure reliability of the instrument. Afterwards, researchers went through each question in the guide for verification and clarity. This gave an opportunity for certain pertinent issues which could not be captured initially to be included in the interview guide. Interviews were conducted either in English or Ndebele language based on the respondents' choice, ensuring better comprehension of questions. Written consent for audio recording of interviews was sought prior the interviews. To ensure confidentiality and privacy, interviews were conducted in a private room at Luveve Youth Centre where youth activities usually take place. At all levels of data collection there was continuous checking of data integrity.

Ethical considerations

Informed consent to participate in the study was obtained from parents and caregivers and age-appropriate assent was obtained from participants ensuring that the consenting process did not accidentally disclose participants' HIV status. Ethical approval for the study was attained from Bulawayo City Health Department Ethics Committee, Luveve Clinic, Great Zimbabwe University Ethics Committee. Confidentiality and anonymity were respected during the data collection process. Participants were assured of privacy and confidentiality. All information obtained was stored in a password-protected computer using pseudonyms. Lastly, the subjects' rights were respected, particularly those who did not have parental consent or refused to participate in the study.

Data processing and analysis

Thematic content analysis was used for data analysis in this study. Thematic content analysis involves

describing content based on themes and comprises three stages: (1) pre-analysis; (2) exploration, treatment; and (3) interpretation (Bardin, 2011 in Oliveira et al., 2016). Audio recorded data were transcribed and translated verbatim into English. After translation, descriptive interview summaries were written for each in-depth interview (IDI). Interview summaries were used to devise a provisional coding framework. IDI interviews were then coded line by line using a coding framework. Names and other identifiers were removed from transcripts before they were entered into NVivo (version 10), a qualitative data storage and retrieval program. Codes were grouped into categories and emerging themes were identified. Themes and sub-themes were exemplified with verbatim quotes. Pseudonyms were used in data presentation.

Validity and reliability of the data

The qualitative approach has at times been thrown the gauntlet by positivists who question the generalisability of findings from small studies and point to a lack of objectivity given the autonomy the researcher has to interpret the data. According to Galofshani (2003), reliability and validity are conceptualised to mean thoroughness, trustworthiness, and quality in a qualitative paradigm. This study's validity and reliability was pinned on design reflexivity because it is mainly centred on the experiences of HIV-positive adolescents in disclosing the status to their romantic partners themselves, rather than generalisations. As a result, the participatory nature and triangulation of data collection tools were important to ensure validity and reliability of findings.

Qualitative research aims to "engage in research that probes for deeper understanding rather than examining surface features" (Johnson, 1995 p.4) and constructivism may be a catalyst toward that aim. Therefore, validity and reliability in this study was improved through the use of constructivism. This was done by valuing HIV-positive adolescents' multiple experiences in their testimonies. Researching with this open-ended perspective advocated by constructivism reinforced our phenomenological approach and data triangulation. Engaging multiple data gathering instruments, such as one-on-one in-depth interviews and participant observations, enabled the researcher to collect reliable, valid and varied experiences and realities of HIV-positive adolescents disclosing their serostatus to their partners. This is attested by Galofshani (2003) who highlighted that reliability and diverse construction of realities is enhanced by engaging multiple methods such as observation, interviews and recordings.

Findings

Factors or circumstances that necessitated disclosure to partners

Fear of reinfection, HIV and AIDS prevention

The desire to prevent transmitting HIV and other sexually transmitted infections (STIs) to partners emerged as the major circumstance necessitating disclosure to partners by HIV-positive adolescents. More so, they highlighted that disclosure gave space for negotiating safer sex, which leads to behaviour change through condom use. The following quotes illustrate this point:

I disclosed to avoid infecting my partner with HIV

through acquiring STIs like gonorrhoea or syphilis (IDI 1, aged 19).

What pushed me to disclose is I wanted him to know the conditions prevailing, how we can plan our future, safe sex practices just in case if he refused to use a condom. Mainly this is what came to my mind, so when I disclosed to him, I could tell that it was not easy for him but final he accepted (IDI 3, 18 years).

Guilty conscience

Some of the HIV-positive adolescents' young mothers who were interviewed (emancipated minors) were pushed by guilty conscience to disclose status. These issues are revealed in the quotes below:

I did not tell anyone immediately, I had many thoughts in the night; I could not sleep so I had to tell my husband. It was not easy but my heart pushed me to tell him. I was feeling bad and I said to myself if I do not tell him, I might die of stress. I told him with a lot of fear that when I went for antenatal care they found me HIV positive (IDI 12, aged 19).

In my case, something inside me just pushed me to do it and it was and still the best thing, trust me (IDI 4, aged 16).

Initial we used protection but then it was eating me up inside because it was like I was living a fake life so I had to tell him (IDI 10, aged 18).

Honesty and trust

The desire to be honest, because the truth will one day come out; as well as desire to gain a closer relationship with partners was described by respondents as another facilitator which necessitated disclosure among HIV positive adolescents to their romantic partners. Similarly, in tandem with honest respondents explained how their religious beliefs helped them with disclosure. They felt that believing made it possible for them to disclose. The above is elaborated by the quotes below:

I decided to disclose to my partner because somehow he was going to know about it therefore I told her so that he can make an informed decision on whether the relationship continues or not (IDI 13, aged 18).

I decided to disclose my status to my partner to build a trustworthy and honest relationship (IDI 10, aged 18).

What helped me to disclose was my faith in God. I did not want to stay with a lie in my heart even afterward (IDI 6, aged 16).

Supportive bodies

The desire for help from the other partners; health care counsellors from clinics, and improvement in knowledge through attending support groups formed by organisations that support young people living with HIV such as AFRICAID Zvandiri programme emerged as some of the facilitators for the disclosure of HIV status to intimate partners. This is expressed below when some of the interviewees had this to say:

We dated two years back little did I know that she is positive too and I was worried about telling her my HIV status, but then my health deteriorated

over time and I asked the health workers to assist me. More than anything I was afraid and ashamed to tell my partner since I did not know her status. However, with encouragement from health workers, it was made possible and we accompany each other sometime or collect medication on behalf of each other if it's time for refilling (IDI 8, aged 18).

With encouragement from health workers, I was empowered to tell my partner as I needed support from her. She accepted it and assured me that she still loves me (IDI 15, aged 19).

Timing

It emerged that some adolescents told their partners when they first meet while others had to wait until later. For those who decided to wait had to do everything to keep partners safe by using condoms. While those in long term relationships tried to find a time when the partner was calm and time for a long conversation. Some of the respondents had to disclose with faith that the disclosure process will yield positive results after careful considering that it was the right time to disclose and it was the right person to receive the news. This is illustrated by the quotes below:

The earlier the better... I thought it was the right time to disclose without knowing that it was the right time to be dumped...he kept quiet and later said "To be in love with an HIV-positive girl is like committing suicide" (IDI 8, aged 18).

Aaaah, I disclosed after eight months after establishing trust and that the relationship was going somewhere (IDI 13, aged 18).

Legal and ethical obligations

The sharing of HIV status should be a personal choice. Conversely, in sexual relationships, it can be a legal obligation regardless of whether or not your partner becomes HIV positive or if the harm was unintentional. One may face criminal charges if a partner accuses one of not disclosing your HIV status in an intimate relationship thus some of the adolescents had to disclose on this basis as illustrated below:

I had to tell him that I am HIV positive because of his pressure to engage in sexual intercourse with me which was mounting. Since I knew my HIV status I did not want to feature on the newspaper headlines based on causing bodily harm (criminalisation of HIV/AIDS) (IDI 14, aged 18).

I felt it as my obligation and my legal duty to inform my partner about my status before anything else to avoid prison in case... my partner, my partner takes me to court for not revealing my status (IDI 11, aged 18).

Just knowing that disclosure is a legal issue makes it feel like you should disclose, so that you are not found wanting (IDI 3, aged 18).

Timing and modality of disclosure

Face-to-face

Some adolescents who were interviewed revealed that they disclosed directly through talking face-to-face on the roadsides where they would meet with their partners. The following quotes illustrate this finding:

My heart throbs each time when I glance and pass through the spot, no human being perished in that spot but my relationship, my love vanished and came to an end like a bathing soap (IDI 13, aged 18).

I used to tell him that there is some confidential information that I wish to share with him, so when we were taking a walk in my hood. I then said, “Bae, I have something to tell you and it is my wish that the information remains between me and you”. As we were looking at each other face to face I told him that I was on ART and I could even see the pain from his eyes after revealing the status (IDI 6, aged 16).

Private place

Most adolescents reported that disclosure was done somewhere private, familiar, relaxed and as soon as possible because the longer you wait, the harder it becomes. Also, many of the participants echoed their preferences for private spaces to ensure that their partners assimilated the information without distraction.

I asked him to come over to my aunt’s place and decided it was now time. I told him it was not easy because it’s an emotional story. I told him I was born with HIV (IDI 11, aged 18).

Initial I wanted to put my clinic cards on the table as soon as possible before she arrives at my house and then take it from there. However she came earlier than I expected. Therefore I had no option but to face the reality, firstly I brought a topic related to HIV in trying to find out her reactions then later said babe I do not know how you will take it but the thing is I am a victim of historical circumstances, not of my choice. I was born HIV positive and it is something I came into this world with (IDI 5, aged 19).

Hospital support through nurse counsellors

Adolescents who were nervous about disclosing their HIV status or feared being threatened by a partner visited their local health clinics to seek help telling their partners and declaring that they might have been exposed to HIV (partner notification) and should get tested.

I got married a year ago and I was worried about telling my wife my HIV status, but then my health deteriorated over time and I asked the health workers to assist me. More than anything I was afraid and ashamed to tell my partner. However, with encouragement from health workers, it was made possible (IDI 8, aged 18).

I already knew my status because I was born with HIV so after 6 months of dating we decided to visit a new start centre to get tested because I did not know how he will react if I disclosed, we got tested he was found negative and I tested positive. He did not abandon me there and there though we did not talk much afterwards (IDI 10, aged 18).

Text message

The study revealed that disclosure also happened in writing via WhatsApp text messages that asked for assurance of privacy, sought support and relational reassurance. Because

the recipient was far away, respondents felt they could communicate better in writing.

I remember I used a WhatsApp to tell him that I am positive (IDI 6, aged 16).

I sent her 640-letter text telling her all the reasons why I loved her and lastly was the burning issue of my HIV-positive status which I could not hold in any longer (IDI 15, aged 19).

Outcomes of HIV-status disclosure

The study found mixed reactions to disclosure to intimate partners, including empathy, disruption of relationships, depression, anger, and emotional and physical support.

Breaches of confidentiality

Negative outcomes included accidental disclosure to others which resulted in discrimination. Stigmatisation was a major finding resulting from HIV-status disclosure to romantic partners. Some experienced positive social outcomes as a result of disclosure, receiving support and appreciation from partners.

We dated for two years and thus I concluded that she is a potential date, and she will be there for me. All these years I have been trying to balance honesty with protecting my right to privacy. As a result, I had to disclose and the news that I am positive spread so now people do not want me around their children because my HIV status is known (IDI 9, aged 18).

To be honest with you there are times where I just cry and wish I was not HIV positive. Like I was going out with this guy at church because of my religious background I had to disclose with the hope that I am in a relationship with a guy who fears God, yet those who fear God are being told that the last thing they should do is marrying someone who is HIV positive as a result the community got to know that I am HIV positive (IDI 13, aged 18).

However, it is important to note that all the respondents raised the need to address stigma and discrimination in their wider communities.

Depression

Respondents who described situations where they were at risk, disclosure was a necessity most notably in settings where they would come into direct contact through sex. This, however, was confronted by distressed moments especially where partners could recall everything that they did. The following verbal narrations by participants explain the issues stated in this paragraph:

Um we used to condomise but he took it off but still I felt bad even though I knew his status because I did not expect it (IDI 1, aged 19).

The moment I heard HIV positive status, my heart stopped beating for a moment and I started crying. I felt that I could not have a proper life considering all the things we did and death was the next thing (IDI 7, aged 17).

Disruption of relationships

The study found that disclosure lead to stressful outcomes, rejection and separation from partners as illustrated below:

At first, he did not accept it, he thought I was joking the following day he called me and said baby are you serious about what you told me yesterday? And I replied yes I am serious. He asked himself whether he should marry this girl who was HIV positive. He made his decision one day he called and told me that he was no longer interested in me because of my status (IDI 1, aged 19).

I started dating when I was 17 but it was never easy to date knowing my status. I was shy and scared which led me to self-discriminate, but in a flash, I realised that the world was for me to choose whether to tell my girlfriend or not. I did and it did not go well. My girlfriend ditched me out and I could not forgive myself and it was as if I was the one who had refused her (IDI 15, aged 19).

Relationship assurance

The study found that disclosure of HIV status to romantic partners was associated with positive outcomes including increased social support, acceptance, decreased anxiety and depression, and reinforcement of relationships. Although fear of negative outcomes was reported as a major barrier to HIV-status disclosure, most individuals who disclosed reported experiencing positive social outcomes. The statements below reflect this:

I have a loving and caring boyfriend. When we were dating I was concerned about the outcome of how he would react when he found out my status. What I feared most was to be rejected. "Is my status important to him?" was the question which kept on ringing in my mind. The answer came I told him that there was something I wanted to tell him. At that moment tears were running down my face. He asked me what the problem was. That was when I told him that I was born HIV positive. He said he loved me for who I am and that, we would overcome this together and he encouraged me to be strong at that moment I felt relieved. Right now we are still together (IDI 13, aged 18).

About six months down the line, then I told him but I would not say he was Okay nor say it did not bother him however he did not leave. I was lucky (IDI 7, aged 17).

Related to the above, one interviewee was bleak about her future because of being HIV-positive. She did not imagine herself tying the knot but her lost hopes were revived as this quotes reveals:

I could not believe it, dream it nor visualise it that a wedding ring would sparkle and shine on my left finger. Although others have got it, their meaning is different mine symbolises true love, with God everything is possible (IDI 13, aged 18).

In my case something inside me just pushed me to do it and it was and still the best thing trust me. When I grew up I always told myself that I want to be in a position any guy I dated about my HIV status and that was a big lie because I realised that life was full of surprises and blissful packages I dated 4 guys in my teenage years; I broke up with all 4 of them at different intervals but felt like they do not deserve

to be told. But it happened that I met up with this fine dude and I felt like there was something about this guy that was special. We dated 6 months and every time I got to see him my heart kept bleeding like I was hiding something away from a person who loves and cares for me that much. I asked him to come over to my aunt's place and decided it was now time. I told him it was not easy because it's an emotional story. I told him, "I was born with HIV". All he managed to do was to get hold of my hand gave me a warm and caring hug and told me it was OK and that no circumstances could ever change the way he felt for me. We are still dating today and he has never changed, he loves me even more than before (IDI 11, aged 18).

Coping mechanisms after disclosure

Social comparison coupled with some form of reasoning was one finding reported by adolescents. The fact that they did not choose to have the virus and were not the only ones with HIV, helped them develop a positive attitude about being positive.

I am happy with HIV because there are diseases that are worse like cancer and diabetes. Just imagine injecting yourself insulin three times a day, with ARVs I just take them once and am done (IDI 6, aged 16).

I'm not the first and last person to suffer from HIV (IDI 2, aged 15).

Guaranteed support for ARV treatment and care from NGOs
Adolescents were able to cope with disclosure because of antiretroviral treatment and local NGOs like AFRICAID, Grass Roots Soccer and the National AIDS Council. Treatment-induced confidence seemed to be high among respondents interviewed, showing that adolescents living with HIV can thrive just like any of their HIV-negative peers because they are provided with support and opportunities that enable them to overcome the challenges they face. Thus, one can deduce that adolescents were aware of the significance of ARVs in reducing death, preventing recurring illness and prolonging life. This was supported when some of the respondents interviewed had this to say:

I have struggled with sickness and sadness in my life as I lost loved ones and learnt of my HIV status. But now with ARVs and the care, we get from clinics and organisations like Grass root soccer, AFRICAID and National AIDS Council I have learnt to accept my HIV status and to look forward to the future (IDI 10, aged 18).

As we think of the future, we too want to be able to enjoy happy relationships and families just like our negative peers but this brings a new set of issues which we are now learning to cope with, can we date and get married?. Like all adolescents we need to abstain until the right time that we have a different experience on different issues but that we all share the common dream of happy, healthy family of their own (IDI 9, aged 18).

Social support

Social support emerged as one of the coping mechanisms used by adolescents after disclosing to the partners. HIV-related social support included reminders to take medication, sharing information about HIV/AIDS as well as emotional support to deal with anger, isolation and distress among other issues. The following quotes from participants illustrate this point.

Take this saying from me behind every good man there is a good woman. I met the one who understands me. I did not know she was positive too until she told me. Now I have the love of my life who I share ideas with. Therefore this means you should take time to study who you will disclose to before you fall in love (IDI 5, aged 19).

Usually, we share HIV-risk-reduction strategies since I have been infected and she is HIV negative (IDI 14, aged 18).

Relatedly, another respondent revealed that taking medication was simple during sleepovers with a partner who is aware of their status, thereby removing the burden of hiding when taking the medication.

My partner is aware of my status and keeps on reminding me, “have you taken your medication?” Adherence to drugs will not only mean you become strong and well but that you can protect your partner from HIV (IDI 1, aged 19).

It is therefore clear that disclosure is critical to retention in care and treatment adherence.

Avoidance of anxiety

Respondents reported that health workers and community treatment supporters counselled them and emphasised that they should avoid worrying about being positive because this would negatively impact on treatment adherence, result in worry and sadness which would in turn plummet into depression and/or anxiety.

Through several counselling sessions I have realised that living with HIV is not the end of the road, now I can take my medication and eat healthy without having to worry about anything (IDI 6, aged 16).

Being HIV positive is not a cause for shame, despair (IDI 10, aged 18).

To reduce their anxiety, participants delved into their academic work and engaged in other extra mural activities such as reading, listening to music, interacting with their peers on social media and doing sport, a prominent pattern amongst participants aged 15–19 years.

Peer support groups

HIV-positive adolescents attended more formal peer support groups to cope with the negative effects of disclosure. Through Africaid Zvandiri support groups, adolescents gained HIV knowledge and reduced their levels of stress by receiving support from peers who had similar experiences. These quotes summarise how support groups help them cope after disclosure:

Peer support groups are crucial for sharing and learning as they provide valuable platforms where other adolescents of my age openly talk and share their experiences (IDI 7, aged 17).

We talk about a lot of issues during support group sessions stigma, social life, adherence among other things and facilitators taught us that if you have a partner you must disclose to them so whatever problem that I encounter haaa ... I know that if I put it across I get relieved for example even if I am not feeling well, my peers from support group come home and pray for me you see (IDI 14, aged 18).

Drawing a parallel with the above, it is worth noting that the majority of respondents reported that disclosure resulted in adherence and retention to care. In addition, they highlighted that they were usually urged by health care workers that adherence only improved if their sexual partners were made aware of their condition and were thus more likely to understand how important the drugs were for survival and well-being, since poor retention and adherence to ART lead to virological resistance and ultimately treatment failure. The following remarks illustrate this:

Disclosure and adherence are Siamese twins. Why? (implying that they are closely associated) Let us say I visit my partner for more than 3 days, how I am I going to take my medication if I have not disclosed? It becomes a challenge, but if he is aware, I will be adhering to medication. He may even remind me; “have you taken your medication?” (IDI 1, aged 19). Yeah and Sister— always stresses that, we should disclose our statuses to partners to ensure ART adherence, viral load suppression and high CD4 count during monthly support groups meetings that we usual attend (IDI 7, aged 17).

Discussion

Many of the adolescents in this study found their circumstances understandable because they had several generalised resistance resources (GRRs) that enabled them to deal with stressors, thereby striking a balance between stressors and resources. Using the salutogenesis framework of Antonovsky (1987) which focusses on factors that support health, GRRs acknowledged in this study were the treatment system comprised of social support groups, partners, ART and understanding. Most participants seemed to have adequate GRRs to deal with their daily stressors. In terms of participation, the adolescents were pro-active in their treatment regimens which they, after being disclosed to, saw as meaningful considering their future and staying healthy. The majority of adolescents in this study saw adhering to their treatment regimen as very important and a challenge worthy of the energy they invested in it. Disclosure enabled them to understand their challenges and experiences and what they needed to do to manage their situation.

Conclusion and recommendations

This study synthesised the experiences of HIV-positive adolescents in disclosing their serostatus to romantic partners. It was evident that disclosure of status to romantic partners was necessitated by circumstances. The decision was never planned by the discloser but was in response to the pressure of circumstances. As a result, it may be said

that disclosure was not always based on choice, that the process is emotional and complex with uncertain outcomes.

Against this backdrop, the following recommendations emerge from our findings about the lived experiences of disclosing HIV-positive status to romantic partners.

Disclosure should begin with self-acceptance

Self-acceptance goes beyond simply telling yourself that you are okay with your status. Instead, it is about how one sees oneself as a person with HIV. This should start by asking how you see the future. Are you optimistic or do you have doubts about the future as a result of the disease? If it is the latter, one may need to work through those issues first, either by meeting with a counsellor or joining a support group of like-minded people who have gone through the same things as you.

Build a support system

Living with HIV does not benefit from complete isolation. Find a trusted friend or family member to turn to for support, someone who understands who you are as a person. By going through the process with someone else, people living with HIV may find positive and effective ways to communicate their experiences and forge a different attitude towards the disease. HIV and isolation are social determinants for the development of depression and anxiety among adolescents; thus, social support is key in reducing the risk of mental disorders among HIV-positive adolescents.

Examine possible reactions

It is important to pose the question: how will I react if I am rejected? Conversely, how will I react if I am not rejected? Accept that your partner is “allowed” to reject you and in the same way you are “allowed” to reject your partner. Both of these scenarios are valid. Therefore, if someone is unwilling or unable to wrap their head around HIV, that is their issue and not yours. In this regard, one may not have challenges accepting the outcomes of HIV disclosure.

Take cognisance the 5 Ws and an H

Who do you need to tell? What do you want to tell them about your illness and what are you expecting from the person to whom you are disclosing your HIV status? When should you tell them? Where is the best place to have this conversation? Why are you telling them? If all these questions are succinctly answered then one is in a good position to disclose.

Disclosure requires one to find a safe place and time

One-on-one, in-person interaction is the best way to approach disclosure. However, it should not be a spur of the moment conversation but should be well planned. Having a safe space is one of the more important criteria because it offers more control and intimacy for trust and safety.

It is imperative that policymakers, implementers and programmers to have a better understanding and appreciation of the experiences that adolescents go through in the process disclosing their HIV-positive status to romantic partners. This will help in the development of frameworks for disclosure to intimate partners that help attain the 95-95-95 targets and the SDGs of ensuring healthy lives and promoting well-being for

all at all ages. Organisations and other relevant stakeholders can learn what works well to ensure retention and adherence to ART, what needs to be strengthened, as well as what is missing from current disclosure practices and toolkits.

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