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Research Article

Influences on decision-making about disclosure of HIV status by adolescents and young adults living with HIV in KwaZulu-Natal, South Africa

Thandeka Smith^{1*} , Janet Seeley^{1,2,3} , Maryam Shahmanesh^{1,3,4} , Christina Psaros⁵ , Chiedza Munikwa⁶  & Nothando Ngwenya^{1,3,4} 

¹Africa Health Research Institute, Mtubatuba, South Africa

²London School of Hygiene and Tropical Medicine, London, United Kingdom

³School of Nursing and Public Health, University of KwaZulu-Natal, Durban, South Africa

⁴Institute for Global Health, University College London, London, United Kingdom

⁵Department of Psychiatry, Harvard Medical School, Massachusetts General Hospital, Boston, USA

⁶Independent Consultant, Polokwane, South Africa

*Correspondence: Thandeka.smith@ahri.org

Background: Adolescents and young adults living with HIV (AYA) are faced with the challenge of living with a life-long chronic condition. We investigated the influences on the decisions by AYA to disclose their HIV status to family, intimate partners and friends.

Methods: Twenty AYA aged between 15 and 24 years were purposely selected through local community-based organisations in eThekweni municipality and uMkhanyakude district in KwaZulu-Natal Province, South Africa. Virtual in-depth interviews were conducted between September 2020 to October 2021 using a topic guide focusing on HIV-status disclosure and the impact of stigma on decision-making capacity. An iterative thematic process was used for analysis.

Results: Findings revealed the challenges that AYA experience for disclosure because of stigma and how this impacts their decision-making capacity. Family and friends influenced AYA in processing their discovery of their HIV status offering support needed to manage living with HIV. However, for some AYA disclosing to relatives, friends and intimate partners was difficult because of fears of rejection and recrimination. The act of disclosure was influenced by both internalised and external stigma and the type of relationships and interactions that AYA had with relatives, friends and caregivers.

Conclusions: The decision to disclose is challenging for AYA because of the fear of rejection, along with internal and external stigma. The provision of support, whether from family or peers, is important. Enhancing the decision-making capacity of AYA is essential for developing their self-esteem as well as supporting future healthcare choices.

Keywords: HIV disclosure, negotiating life, self-identity, social factors, socio-ecological approach, young people

Background

Globally, 39 million people were living with HIV by July 2023 (UNAIDS, 2023). Among these, nearly 1.65 million were adolescents aged 10–19 years. In 2022, about 480 000 young people aged 10–19 years were newly infected with HIV (UNICEF, 2023a). Eighty-five per cent of young people living with HIV live in sub-Saharan Africa, with the majority of those in southern Africa (UNICEF, 2023b). Each of these young people, on learning of their diagnosis, is faced with decisions about who to share this information with, beyond the healthcare worker and perhaps the caregiver who disclosed their status to them. Managing disclosure, while anticipating the consequences of sharing their HIV status with friends and family, often makes the decision to share challenging (Kidman & Violari, 2020).

For this study, we define adolescents as aged between 15 and 19 years. This is a period of physical change marked by an overall physical growth spurt and sexual maturation, known as puberty, although timing may vary by gender, cohort and culture (Hopkins, 2014). We define young adults as those aged 20 to 24 (Aurpibul et al., 2023; Fair & Jutras, 2022). We use the abbreviation AYA in this article to stand for “adolescents and young adults living with HIV” (i.e. age range of 15 to 24 years).

Antiretroviral therapy (ART) has made it possible for children who acquired HIV vertically to live into adulthood, requiring families, healthcare providers and other stakeholders to develop care approaches for the disclosure of the child’s diagnosis to them (Aurpibul et al., 2023; Gabbidon et al., 2020; Madiba & Mokgatle, 2016). When, to whom, with whom, what and how to disclose are important

aspects of this process of disclosure to the child and then thereafter to other people in the family or social network (Afifi & Afifi, 2015; Madiba & Mokgatle, 2015; Namukwaya et al., 2017). How should a condition that carries with it potential stigma be disclosed to a person without causing harm and suffering to the individual in question?

A major developmental process during adolescence and early adulthood involves establishing one's own identity and independence (Branje et al., 2021; Saewyc, 2017). Doing this while managing to live with HIV is particularly challenging for AYA, who face significant clinical and psychosocial issues, including challenges to their retention in care and adherence to treatment (Chaudoir et al., 2011). Adolescence and early adulthood are transition periods, in which building social relationships with peers plays an important part in identity development and close friendships and intimate relationships become important (Karp, 1986). However, the stigma linked to HIV presents AYA with challenges, which can make it difficult to be open about HIV. The fear of stigmatisation may affect their decision-making capacity about disclosure to other people (Kippax et al., 2013) because disclosing one's HIV status to a partner, for example, can have both undesirable (e.g. the loss of that partner) and desirable (e.g. strengthening the relationship) consequences (Betsch et al., 2016; Boyd et al., 2020; Crowley et al., 2019).

For AYA, their experiences and challenges vary, not only by the context in which they live and grow up but also between those who acquired HIV as adolescents and those who acquired HIV as infants (Boyd et al., 2020; Coughlin, 2016). Individual AYA may handle the challenges they face differently, including managing ART adherence, dealing with stigma, coping with a lack of emotional support and addressing harmful gender norms, which may affect their clinical and psychosocial outcomes (Abubakari et al., 2021; MacCarthy et al., 2019; MacCarthy et al., 2018). How they manage these challenges can have an impact on their decision-making capacity or the perception they have of their control of their situation which influences healthcare seeking behaviours and the ability to self-care (Magidson et al., 2019).

The decision-making of AYA is nested within multiple levels of influences of disclosure and stigma. The relationship factors are situated within a relationship context (family relationship and parent–child relationship) and relationships are, in turn, shaped by the sociocultural environment (e.g. HIV-related stigma). Thus, relationships and sociocultural factors influence the dynamics of the process of decision-making and the outcomes.

In this article, we examined decision-making capacity about disclosure amongst AYA in the municipality of eThekweni and the district of uMkhanyakude in KwaZulu-Natal province, South Africa. More specifically, we considered the extent of disclosure, and identified which factors influenced the decision of AYA to disclose to specific people. We define decision-making capacity as an individual's capacity to determine and make meaning from their environment through purposive consciousness and reflective and creative action (Houston, 2010). People shape their life-course through the choices and actions they take within the opportunities and constraints of their life experiences and social setting (Elder Jr, 1998).

Existing theoretical models on HIV disclosure have theorised that the decision-making is a process of assessing and calculating perceived benefits and risks related to the disclosure (Chaudoir et al., 2011). While increasing numbers of interventions encourage culturally and developmentally appropriate adult disclosure in resource-limited settings (Gabbidon et al., 2020; Rochat et al., 2014), there is still a gap in understanding the dynamics of decision-making amongst AYA about disclosure of their HIV status (Gabbidon et al., 2020).

Our analysis was guided by a socio-ecological approach based on the work of Bronfenbrenner (2000), to look at the different levels of influence on AYA decision-making. We initially focused on the individual, relationship, community and societal factors which shape and influence decisions (Qiao et al., 2015). This approach helped us to set out the range of factors that influence decision-making, identifying facilitators and barriers to decision-making of AYA. As explained below in our methods section, during analysis we condensed these factors into the intra- and inter-personal levels of influence for the presentation of the results in this article.

Methods

Setting

uMkhanyakude district municipality has a population of about 650 000 people (UKDM, 2023) and is characterised by poverty, unemployment, poor infrastructure and temporary local migration, with family members dependent on small-scale agriculture and allowances from migrant workers and government grants. The district is one of the poorest in South Africa, with high HIV prevalence of more than 40% and poor access to resources, with only about 22% of the population having access to piped water and sanitation (Chimbindi et al., 2018; Gareta et al., 2021).

eThekweni municipality has a population of 3.5 million people (STATS SA, 2023), accounting for 35% of the total population of KwaZulu-Natal province. Close to 30% of the population is under the age of 15 years and 63% of the population is under the age of 35 (Simbayi et al., 2019). Two million of eThekweni's residents live below the upper bounds of the poverty line of ZAR 1 227 (≈US\$60) per person per month, and 17.1% of the population reported having no income in a 2016 survey (STATS SA, 2017).

Data collection took place between September 2020 and October 2021 during the COVID-19 pandemic, which resulted in data being collected virtually. COVID-19 was declared a global health emergency in January 2020 and a pandemic in March 2020 (García-Basteiro et al., 2020). Governments worldwide, including South Africa, subsequently implemented public health emergency measures, including legally enforced closures and limitations on the maximum capacity of places where people congregate (e.g. schools, stores, and recreational facilities), physical distancing, mask wearing, limitations on nonessential domestic and international travel, and self-isolation or quarantine requirements (Campbell et al., 2022). These measures disrupted participation in work, research, education, travel, recreation, exercise and physical activity.

Study participants

We recruited 20 AYA aged 15–24 years from urban and rural KwaZulu-Natal (eThekweni municipality and uMkhanyakude district). Recruitment was done through local community-based organisations. The 20 participants had acquired HIV either perinatally or through sexual intercourse. A non-probability sampling strategy was used to purposively select a broad spectrum of AYA, from urban and rural settings. The sample consisted of school-going, non-school-going, tertiary education-going, employed, unemployed and self-employed individuals, in order to capture a range of different types of individuals, relationship and community experience. Through word-of-mouth we were able to find potential participants not linked to care, but they declined to participate in the study. However, we facilitated access for these young people to be referred to and linked to care.

Data collection

Peer-researchers who had first-hand experience of negotiating life living with HIV in the study setting conducted the interviews and were engaged in data analysis and interpretation. The peer-researchers were trained in interviewing skills by TS and NN. All the peer-researchers spoke both the local native language, isiZulu, and English. The participants engaged with the peer-researchers telephonically and over video calls to assess their eligibility and willingness to participate, as well as provide further information and gain informed consent. The peer-researchers explained that participation involved taking part in up to three in-depth interviews which allowed for the capturing of evolving processes and change over time in AYA decision-making about disclosure. Recorded informed consent was collected from all the participants. Confidentiality was ensured by conducting interviews from private rooms in the peer-researchers' homes and advising the study participants to find private spaces to engage in the interviews. The interviews were audio-recorded and later transcribed and translated into English.

The interviews focused on the aspects that influenced AYA decision-making capacity on disclosure, guided by the socio-ecological framework of the different levels of individual, relationship, community and society. The first interview focused on decision-making, particularly big decisions that AYA may have made in their lives. The topic guide focused on what had impacted those decisions by asking knowledge, experiential and feeling-related questions. The aim was to probe to understand the daily choices of AYA and the influences that had an impact on those choices. The second interview focused on health literacy, knowledge of their HIV status, information they received formally and informally regarding HIV and how they may have used that information to make decisions in their everyday lives. The final interview focused on feeling-related questions, how their emotions impacted their everyday lives and the choices they make.

Data (the transcripts from the interviews) across the respondents were compared as the study progressed, and similar types of information began to emerge, which gave confidence that by the end of the third interview saturation had been reached on the topics under investigation.

Data processing and analysis

An initial coding framework was developed, based on the topic guides, with broad codes drawn from the topics covered in the interviews. The peer-researchers and research team reviewed and discussed an initial set of transcripts. Two authors (TS and NN) later discussed difficult coding segments, refined the broad codes with sub-codes and yielded a final coding framework reflective of both a priori codes and emergent codes reflecting phenomena and concepts derived from inductive coding of the data. Codebook definitions and examples of code applications were reviewed throughout the analysis period. We used thematic analysis with the resulting coded excerpts. We then undertook a deeper analysis of transcript excerpts via re-coding for themes related to the themes of disclosure and stigma. Subgroup analyses from this re-coding were restricted to identifying the links between status discovery, self-disclosure and internalised/ externalised stigma with decision-making capacity, and then linking these experiences to the different levels of the socio-ecological framework, and finally grouping them into two broad categories for this article: the intrapersonal influences and the interpersonal influences on decision-making. The decision was taken to use these two overarching codes because of the overlap in the interpersonal material which related to the relationship, community and society levels.

Ethical approval

Ethical review and approval were provided by the University of KwaZulu-Natal's Research Office through the Biomedical Research Ethics Committee (BREC/00000661/2019). Africa Health Research Institute (AHRI) and AHRI Community Advisory Board all approved this study as minimal risk to all participants, including minors. All participants provided recorded informed consent.

Results

Initially 20 AYA were approached to take part in the study, but three refused, and one initially expressed interest and participated in the first interview. However, after being approached for the second interview, she withdrew because she said she was not living with HIV. The 16 other participants completed the three in-depth qualitative virtual interviews successfully. In order to meet the aim of having a sample size of twenty AYA, four additional participants were recruited who took part in the in-depth interviews. Thus, in all, 20 participants took part in the in-depth interviews.

All the participants were aged 15–24 years and in line with our sample requirements, as outlined above. Table 1 summarises participants' demographic details.

Below, we present the findings supported by excerpts from the narratives of the AYA, looking at the intra- and interpersonal influences on decision-making capacity. All the participants described the moment they discovered their HIV status/received their HIV diagnosis, how they (and their families) coped with that diagnosis, and their perceptions and experiences of living with HIV individually and within their families and wider relationships. Stigma and disclosure decisions repeatedly emerged as affecting ART adherence

Table 1: Participant characteristics

Factor	Number
Age	
15–19	6
20–24	14
Highest level of education	
Primary or less	0
Secondary	14
Diploma	4
University	2
Current employment	
Employed by someone else	4
Self-employed	2
Unemployed	2
At school	12
HIV acquisition	
Perinatally	10
Sexually	7
Unknown	3

and clinic attendance and informed the types of relationships they established within their social networks.

Intrapersonal influences

All the AYA in the study shared a similar first reaction to learning about their HIV status. They had all felt frustration and fear of the future. They talked of struggling to know how to act and behave. They said that they lacked information on how to deal with this new knowledge. Some expressed feelings of isolation and how this information made them feel different from their friends. Some commented on the fear of infecting their friends and other people they were close to. A 15-year-old young woman told us how she felt:

Well, I felt a bit broken ... I felt I was different from my friends, I was scared to be with my friends, and I started playing alone because I thought I would also infect my friends who do not have it. So, it really affected me because I lost some friends, [and] I never used to play because I was scared.

Others also talked about emotional pain and the loss of friends as they isolated themselves from others. This pain and isolation had led to one young woman, aged 24 years old, considering taking her own life:

Ya, I once thought ... [I] had suicidal thoughts because I was afraid of living with it (HIV) after having learned that I was infected with it, and it felt as if my death was imminent, but the painful part was that I found out late, I was born with it but discovered that late. So, I could not live well, and I would feel emotional when it was time for me to take the pills.

There were many challenges for the AYA as they learned about living with HIV. Most participants were filled with internal doubts about who they were and what their place was in the world. They questioned themselves and questioned their identity as they tried to accept themselves as individuals living with HIV, with some wondering if the information about their HIV status was true.

As time passed, all the AYA decided to accept their HIV diagnosis. This acceptance came as they gained a greater understanding of their condition and acknowledged the

impact on their lives as well as the consequences of being on life-long treatment. A 23-year-old woman shared:

To be true, honest, I haven't achieved any goals, but I'm happy where I am ... Okay the thing that happened to me is that I always had questions like, "Why am I positive?" I so wish my mom was here to ask those questions, but at the end of the day I just realised that no, let me just accept who I am and love who I am because my mother will never wake up and just tell me ... why she left me with HIV positive, with HIV you know. So, I just accepted myself, who I am and I'm grateful, yeah.

Others too came to terms with their status, but some still expressed anger about what had happened to them, as explained by this 24-year-old man:

I was angry at my mum, my family, my friends and even angry at God. I felt that I had not been sexually active, and I didn't even have a girlfriend at the time and so for me it was a huge challenge. I was forced to grow up and, even though I was young, but I had to start making decisions as a 10-year-old and think about how the decisions that I would be making affect me.

Choosing to acknowledge and accept one's HIV status was a personal decision that these AYA had had to make. While others may have been there to tell them about their status and provide advice, accepting that they were living with HIV was something each young person had to do for themselves. It was in the interpersonal environment – their lives with family, with friends and in interacting in the wider society – which shaped the ways in which AYA learned to live with HIV. This included their decision-making about who they felt able to tell about their HIV status. It is these interpersonal factors to which we now turn.

Interpersonal level

Disclosure to AYA

According to most AYA in this study, they had acquired HIV from their mother. However, all of them said that they had not been aware of their diagnosis until they were between the ages of nine and fifteen. Some of them had already been initiated on treatment before their status was disclosed to them. They had been made aware that they have an illness but not told what kind of illness it was. As they grew a bit older, they became inquisitive about the medication they were taking regularly and clinic/doctor visits they used to have. As a result of the questions that they asked family and clinic staff, they learned about their HIV status. A 24-year-old man recalled his experience:

At age 9 or 10 years old, I started asking questions about the medication I was taking daily, and I asked my aunt first and she told me to go and ask my mum what it was for. I went and asked my mother, but she kept on saying it was for flu or different stories each time that I asked, I then decided to ask the doctor during my appointment visit to him and he told me that I am living with HIV.

A 24-year-old woman recalled learning of her status in hospital when she went for tests with her grandmother, when she was a child:

[I was] so thin, you know, so they decided to take us

to hospital ... when we arrived, we were told that we must stay at the hospital because, okay they were going to run some tests and they did, and they told my grandmother that I am actually positive so we must stay there for diagnosis, you know

However, some older family members and guardians who were aware of the AYA's status were often the ones who delayed disclosure due to fear of how the young person would manage due to potential discrimination. They had told the AYA that they had been waiting for them to reach a certain age, hoping that their level of understanding would have improved. These delays, and the reluctance to discuss HIV with AYA in their care, undoubtedly contributed to a wariness among AYA about other people knowing their status; they viewed this information as a secret to be protected.

Family and peer support

Each young person described the ways in which people in their social networks had influenced their decisions to disclose or not disclose their status to others. Some looked for selected people to whom they could disclose their status and who could support them in adhering to their medication regimes and in their daily lives. These decisions were made with great care, because the fear of stigma – once their HIV status became known – made many of the young people reluctant to open up to family members and friends about their need for support. Those who felt particularly isolated had to weigh up the choice of getting support against the risk of sharing with someone who might abuse their position of power when they obtained private knowledge about the AYA's status. Such people could add to stigma and shame by, perhaps, vicariously sharing the information they had. These actions could isolate and damage an AYA at a particularly vulnerable time in their lives.

For the majority of AYA in the study, it was their family which provided them with crucial support and encouragement, including practical, financial and treatment adherence support. While most AYA who had shared their status with their families found the experience supportive, some expressed frustration about managing the situation where their family members wanted to provide advice and support in ways they found difficult. A 24-year-old woman explained the challenges she faced, even though she accepted that her family behaved in this way because they cared:

They were just advising me to take care of myself that way. I must not do drugs when I'm on pills. No, it is my family. Only family tells me that. I feel so shocked and feel a bit disappointed, you know. Because I don't like, I don't feel comfortable when my family is giving me all the advice, I would prefer a non-family member to tell me that ... like a friend of mine, you know, yeah. Yes, they do it because they care. Yes, I do follow their advice, I do a lot.

Not all AYA felt comfortable disclosing their status to their family members. For some, like the 23-year-old woman quoted above, the person they wanted support from – in her case, her mother – had died and was not available to provide support. Those who had not shared their status with their families spoke of their fear of rejection and of managing the

pressure that might come from family wanting to control their behaviour, including their opportunities to have boyfriends or girlfriends. A 24-year-old woman described her decision to disclose her status to her friend and not to her family as follows:

My grandmother, you see we share a good bond; however, when it comes to girl stuff, we don't talk very much about that ... it is one of my friends. She's always been there for me; I don't want to lie. No matter what the situation, but she is able to completely change how I feel, you see. With my family I am not always able to share some deeper things with them and I spend most of my time being alone in the bedroom studying or just on my phone, you see, stuff like that, and so when my friend comes over, I am able to share stuff with them. When it comes to others, I know that these are not people I can easily communicate with, you see.

Whether from family or from friends, the AYA said that they found that having a support system gave them people to lean on when facing life's stressors as they learned to live with HIV. They talked of certain family members or particular friends providing emotional support within their social networks and creating a safe environment for them to be themselves. They said that with those individuals they felt accepted for who they were, motivated to adhere to treatment, and free to express themselves without fear of being judged. Because of this support, many AYA talked of these supporters as having a positive impact on their lives, which had enabled them to now have a positive outlook on life themselves (unlike the negative feelings they had had when they first learned of their status). A 23-year-old woman described the closeness of her bond with the friend she had disclosed to like this:

I cried, she cried, but she was a friend to me, she never judged me, you know, she loved me. I remember when I used to go to sleep over at her house, she would always say, "Friend, don't forget to take your medication".

A 24-year-old man expressed similar gratitude for his friend who provided him with support:

I felt so relieved, I felt, I walked through my community like there was no weight on my shoulders, honestly yeah ... and it was a shock to him, but he was like, "Yeah, so what? You're still my friend," and I thought that maybe those were just words and from that day, days after that, years after that and still up to this day he, we are still friends.

However, not all friends were supportive, and some participants spoke of the fear of discrimination and ridicule if their friends found out that they were living with HIV. A 15-year-old young woman talked about her fears of stigma at school:

I find it hard to disclose my status to them [her friends]. I just think that people will know my status and discriminate against me. At school there would be lessons about HIV and AIDS and often my classmate would make fun of people living with it. I used to feel out of place and fear that they would make me a laughingstock too if they were to find out

that I am living with HIV. I have not disclosed it due to fear that my friends might discriminate against me.

There were a few AYA who said that they had unsupportive family members and partners. Those who had lost both their parents said that orphanhood contributed to them not having the kind of support that they knew other people received. A 24-year-old woman commented:

Some families are supportive, and you find that young people are supported by their mothers and fathers, but not all of us have that luxury. Some families are only interested in what you have achieved.

A 23-year-old woman described the challenges she faced because of a lack of support:

I realised also that I lack people who can support me in this; I am disadvantaged in that I do not have parents like other young people who can assist them with finding a college they could go to and so I ended up navigating that direction on my own and I told myself that even though I am not sure how, but I am going to get to where I am propelled to be.

Most participants lived with at least one parent/caregiver and a sibling or another member of their close family. The AYA talked about the influence that these close family members had on decisions in their lives, beyond managing their HIV status. They talked about the influence on school choices and attendance (including when they left school) as well as decisions about the types of further education they may seek or the jobs they may apply for. The AYA commented that it was impressed on them by their relatives that taking their treatment and staying healthy opened up education and employment opportunities and gave them future choices.

Managing intimate relationships

The AYA in the study experienced dating and relationship dilemmas in their quest for long-lasting relationships. Most of them worried about how the next person they started a relationship with would react if they disclosed their status to them. Fear of rejection was given as a reason why some of the AYA said that they chose to avoid intimate relationships. While nearly all indicated that they had partners in their lives, some said that they had decided not to engage in sexual activities and did not want to disclose their HIV status.

The prejudice that they feared was reflected in choosing not to be sexually active or in a relationship. A 24-year-old woman explained her approach to managing her relationship with her boyfriend as follows:

This is our fifth year. No, I have not yet disclosed my status to him, I am still testing him. Sexual relations are something I am still avoiding right now. He doesn't understand that I am not ready, and recently he has been complaining that I don't trust him, but I did try to cover it up and told him that I do trust him, it's just that I am not ready.

Another young woman described how she had disclosed her status to a previous boyfriend, but he had reacted negatively, so she then resolved to “keep quiet” about her status in future relationships. A 23-year-old man explained how much he wanted a relationship but felt unable to:

I would love to be honest with you when it comes

to dating. I don't think I was created for it although I am a loving person. I am also looking for a partner and I would love to get married some day and just be normal like other people but whenever I try to be involved with someone ... when we begin the relationship and try to do [have a relationship]...it is not the same ...

He concluded that things looked bad for him in terms of finding a long-term partner and he “wondered why [he] even bothered to try”.

The fear of stigma and discrimination cast a shadow over the lives of all the AYA in the study. Concern over what others may think of them, say about them, and possibly do to them, influenced the decisions the young people made about who they would disclose their HIV status to. A desire to be the same as other young people, who did not have a daily reminder of HIV in the treatment they took, meant that for some AYA establishing an intimate relationship involved withholding information about their status. The growing capacity of AYA to make decisions not only involved deciding with whom to share their private information, but also the decision about who they would hide that information from as they navigated their way in an expanding world beyond their home.

Discussion

This qualitative study conducted among AYA investigated the influences on their decision-making capacity. The autonomy they have is dependent on their age, where they live, who they live with and whether they are working or are in school. The findings show how managing stigma through selective disclosure to trusted allies leads to an increased sense of decision-making capacity and better health outcomes among AYA during a key developmental life stage of adolescence and young adulthood. This essential skill of decision-making is developed partly by resisting HIV stigma through selective disclosure to trusted family and friends, and through identifying and finding support structures.

The AYA in this study stressed the importance of support systems at home, in the community and among friends and peers to help them to manage living with HIV. Countering the stigma they faced, or feared they would face, was an important concern in who they chose to trust, a finding corroborated in the work of Harper et al. (2014). They noted the limits placed on social network formation for AYA fearful of disclosing their status, or having their status disclosed, to too many people.

Our evidence suggests that learning to navigate stigma as an individual (in terms of countering self-stigma, for example) and how to manage interpersonal relationships permits decision-making capacity to mature in AYA. As is the case for other people living with HIV (Lowther et al., 2014), taking ART for AYA can serve as a daily reminder of HIV and, because of their fear of being seen taking their medication, can increase their experience of stigma (Kip et al., 2022). Yet, during a time of critical life-course transitions, the AYA in our study were already engaged in finding ways to manage healthcare for themselves, while wanting to become invested in taking greater responsibility for their own health (Dahourou et al., 2017; MacCarthy et al., 2018).

Our findings highlight barriers to disclosure, strategies to avoid disclosure, and fears about, as well as experience of, the consequences of disclosure. The majority of the AYA in relationships expressed anxieties around partner abandonment or fears of their partners perceiving them to be promiscuous. Exercising their agency in non-disclosure became a protective measure for the young people, findings which echo the work of Fair and Albright (2012) in the USA.

We were told by AYA that some parents and guardians kept their children's HIV status a secret, waiting for the young person to become mature. These findings mirror those of previous studies that have examined challenges that face AYA, where parents were reluctant to reveal their child's HIV status. This is typically attributable to a desire to protect their child from psychological distress (Aurpibul et al., 2023; Knight et al., 2023; Madiba & Mokgatle, 2016), to prevent disclosure of the mother's HIV status, and to avoid not only having to address their own feelings of guilt at having infected their child, but also possible blame from their child (Fladseth et al., 2015; Madiba & Mokgatle, 2015). The literature also describes AYA feeling dejected and experiencing emotional stress because they feel a lack of control over what is happening to them, due to their uncertainty of how they acquired HIV (Madiba & Mokgatle, 2016).

Decision-making capacity in terms of understanding, appreciating, reasoning and expressing a choice (Appelbaum, 2007) is integral to understanding how AYA exercise their own power to make and act upon intentional decisions based on available knowledge. Supporting AYA to develop their decision-making capacity is critical for their management of their condition, given that they are in a developmental stage in which they experience impulsivity and a desire for sexual experimentation, but often lack the ability to envision the resulting long-term risks (Madiba & Mokgatle, 2016). During this period, AYA are shaping their identity and are flexible to change and influence.

Many AYA face challenges in dating and relationships. Most of the AYA in our study were worried about how the next person they started a relationship with would react if they were to disclose their status to them. Yet again, fear of rejection from disclosing their HIV status was highlighted as one of the reasons why some of them chose to avoid intimate relationships. This hesitancy to engage in intimate relationships and a reluctance to disclose their HIV status has also been noted among women concerned about undesirable consequences of disclosing their HIV status. Because of mistrust, stigma and the potential loss of a relationship and its social and economic security, women, including young women, may live with partners for some time without disclosing their status (Bhatia et al., 2017; Toska et al., 2015; Viljoen et al., 2021).

The practice of disclosure is not just a single individual event (Viljoen et al., 2021) but is embedded in certain social relationships and a specific sociocultural context (Chaudoir et al., 2011). In this respect, it is important to note that some researchers have pointed out that the meanings and behaviours related to disclosure are variable and dependent on changes within the individual and those in social networks over time (Krishnaratne et al., 2020; Major et al., 1998; Moshabela et al., 2016; Toska et al., 2015). This suggests that there may be opportunities to support positive changes

among AYA. Also, interventions may be required at different points in time to support disclosure and treatment adherence differently, as well as to counter stigma and discrimination, as AYA move towards adulthood and through their life course because of changes in their relationships and social environments.

Limitations

The scope of the study was limited to uMkhanyakude district and eThekweni municipality of KwaZulu-Natal province and a relatively small sample of 20 AYA. However, we were able to gather detailed information over time from these young people. We faced challenges recruiting AYA as peer-researchers. We had to bear in mind that AYA are not a homogenous group, as they have different histories, identities and social networks and many may not wish to openly acknowledge their status by engaging as a peer-researcher. Working with peer-researchers may also have affected data collection both negatively and positively, as there was a risk that they might have become involved in the emotional difficulties expressed by the participants (St Clair-Sullivan et al., 2019). Support was available for peer-researchers if they required it as a result of their engagement in this study.

Due to COVID-19 protocols and social-distancing restrictions, interviews were conducted virtually which made the building of rapport more challenging than meeting face-to-face, a limitation also faced by others (see, for example, Hensen et al., 2021).

Conclusion

There is a need for a better collective understanding of decision-making among AYA, and how disclosure and stigma influence their decisions, which, in turn, will inform their long-term lifestyle and behaviour. A challenge to decision-making capacity among AYA is status disclosure, due to fear of rejection, along with internal and external stigma. Although this study involved only 20 AYA, our findings have given us a glimpse of how AYA consider their decision-making. Our findings highlight how HIV remains a stigmatised condition that leaves AYA vulnerable. As has been illustrated in other work (see, for example, Mark et al., 2019; Snyder et al., 2014), building support groups for and with AYA allows them to draw strength from friendship and companionship, which can support their decision-making. Building such support for decision-making capacity in disclosure of AYA is critical in addressing stigma and developing their self-esteem, which are fundamental in their own healthcare choices and broader decision-making in life.

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ORCID iDs

Thandeka Smith – <https://orcid.org/0009-0002-4146-5376>

Janet Seeley – <https://orcid.org/0000-0002-0583-5272>

Maryam Shahmanesh – <https://orcid.org/0000-0001-7129-8535>

Christina Psaros – <https://orcid.org/0000-0002-0705-2239>

Chiedza Munikwa – <https://orcid.org/0000-0001-7593-7613>

Nothando Ngwenya – <https://orcid.org/0000-0002-5630-6389>

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