

# Parents' perceptions of ethical issues in adolescents' HIV care and treatment at Temeke Regional Referral Hospital, Tanzania

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**Background.** Decisions to test, enrol and disclose HIV status are among the ethical challenges that may influence adherence to antiretroviral therapy (ART) and HIV care and treatment in adolescents living with HIV. In the Tanzanian setting, how parental perceptions of ethical issues affect adolescents' adherence to HIV care and treatment is not well known.

**Objective.** To explore parental perceptions of ethical issues in adolescent HIV care and treatment.

**Methods.** The study employed a descriptive qualitative exploratory design and was conducted at Temeke Regional Referral Hospital in Dar es Salaam Care and Treatment Centre (CTC) in the Outpatient Department (OPD). The study population were parents and non-parent caregivers of HIV-infected adolescents 10 - 19 years of age. A total of 16 persons participated in semi-structured interviews after their consent was obtained. All interviews were audiotaped, transcribed verbatim in Swahili and back-translated into English. An inductive content analysis was used, and standards of qualitative rigour applied.

**Results.** Three qualitative themes emerged: balancing adolescents' autonomy with parents' desire to protect their children; parental dilemmas regarding disclosure of adolescents' HIV status; and parental reasons for delayed disclosure.

**Conclusion.** Participants perceived that parental authority should override adolescents' autonomy in HIV care and treatment. Disclosure of HIV status to adolescents is a challenge to parents. Delays in disclosure often occur because parents feel guilty and because they have fears of rejection by their adolescent children.

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HIV remains a constant threat to the lives of adolescents in Tanzania. Indeed, the United Nations Children's Fund (UNICEF) reported in 2019 that about 1.7 million individuals are living with HIV in Tanzania and nearly 100 000 adolescents between the ages of 10 and 19 are infected with the virus.<sup>[1]</sup> In Tanzania, there is a high prevalence of HIV among adolescents, low uptake of voluntary HIV counselling, low testing rates, and poor adherence to HIV care and treatment.<sup>[2]</sup> Even after testing and enrolment in health service programmes, adolescents' adherence to care for their disease is poor.<sup>[3,4]</sup>

Adolescent enrolment in HIV Care and Treatment Clinics (CTC) in Tanzania is crucial to ending the prevalence of HIV in Tanzania and to contributing to the end of the global HIV pandemic.<sup>[5]</sup> Parents play an important role in HIV-positive adolescents' enrolment in and adherence to antiretroviral therapy (ART) – a therapy that can save the lives of these adolescents.<sup>[6]</sup> There is often tension between the parents' or non-parent primary caregivers' desire to protect their adolescent and the recognition that adolescents need to take a leading role in their own lives, including healthcare decisions.<sup>[7]</sup> This ethical tension raises many questions on how to balance the growing

autonomy of the adolescent by respecting their right to make independent decisions, yet also recognising the role of parents who want to protect their children from harm. Therefore, there are ethical concerns about who makes the consent decisions to enrol adolescents in HIV care and treatment, who discloses the HIV status to adolescents and others, and how these concerns influence adolescents' adherence to ART. Ethical issues that might arise during HIV care and treatment in Tanzania include stakeholders' decisions surrounding HIV testing and enrolment in an HIV CTC,<sup>[8]</sup> disclosure of HIV status to adolescents by their parents, as well as disclosure of adolescent HIV status by the adolescent to the parent (when the adolescent is tested without parental consent).<sup>[9]</sup> These issues may cause distress and disharmony in families and affect the adolescent's adherence to life-saving therapy. Finally, adolescents might also stop attending the clinic for fear of stigmatisation and discomfort as a result of unresolved ethical dilemmas within their own families.<sup>[10]</sup> Parental perceptions of the ethical issues that may influence adolescents' adherence to HIV care and treatment are of utmost importance in developing strategies and interventions to improve the care of adolescents living with HIV, but

this is understudied in Tanzania. Therefore, the research question that we sought to understand was the following: What ethical issues do parents or caregivers identify that influence adolescents' enrolment in and adherence to ART among adolescents attending CTCs in Temeke Regional Referral Hospital?

## Methods

### Study design and setting

An exploratory qualitative descriptive design was used to gain insights into parents' perceptions of the ethical issues that influenced their adolescents' enrolment in and adherence to ART within the African context.<sup>[11]</sup> This study was part of a larger study on adolescents' experience of ethical challenges during enrolment in and adherence to ART in Temeke Regional Referral Hospital, Dar es Salaam, Tanzania.<sup>[12]</sup> Temeke Regional Referral Hospital was also the setting for the current study. This is a large urban hospital that conducts CTCs for adolescents every Saturday, generally seeing 20 - 30 adolescents per day. Saturday was chosen for data collection to accommodate adolescents' busy school lives and their other activities. The study was conducted between January and August 2020.

### Study population and sampling

The study population consisted of parents or non-parent primary caregivers of adolescents who attended the CTC. Purposive sampling was used to recruit parents or caregivers where parents or non-parent primary caregivers of adolescents were eligible to participate if their adolescent had recently participated in a study of their experiences at the CTC and adherence to ART and they were willing to provide informed consent.

### Data collection

An interview guide was developed by the research team and pilot tested at Amana Regional Referral Hospital in Dar es Salaam, Tanzania. Four parents and non-parent primary caregivers took part in the pilot prior to the full study. Slight changes were made to the interview guide based on some questions that did not elicit the required information. Participants were asked open-ended questions to solicit their descriptions of decision-making for adolescents' enrolment for HIV care and treatment; their opinions on adolescents' autonomy v. parental authority; as well as concerns regarding disclosure of HIV status to their children. Probing was done in areas that needed more clarification or elaboration. Interviews were conducted in Swahili and audiotaped with the participants' consent. Each interview generally lasted a few minutes.

### Data analysis

Audiotaped interviews were first transcribed verbatim and then translated from Swahili to English. The interview transcripts were analysed using qualitative content analysis following the guidelines of Graneheim and Lundman.<sup>[13]</sup> Qualitative content analysis offers development of categories from the text data inductively.<sup>[14]</sup> The full transcripts and field notes were first read and reread by all authors so that they could familiarise themselves with the data and the context. Condensed meaning units were then formed through data reduction. These were related to perceptions of parents and non-parent primary caregivers on ethical issues in HIV care enrolment and ART adherence of adolescents. The condensed meaning units

were read and reread to extract the codes. With the assistance of a qualitative software program (NVivo; QSR International, USA), the first author extracted primary codes, which were shared, discussed, revisited and final codes agreed upon by all authors. Similar codes were grouped together and through constant comparison were abstracted into subcategories. Subcategories were further analysed to distinguish their similarities and differences. Similar subcategories were sorted to form categories that reflected the manifest content of the text.

### Ethical consideration

The research followed the ethical guidelines of human subject protection by obtaining ethical clearance from Muhimbili University of Health and Allied Sciences Institutional Review Board (ref. no. DA.282/298/01.C/) and the National Health Research Ethics Committee (ref. no. NIMR/HQ/R.8a/vol.IX/3299). Informed consent was then obtained from the participants. Confidentiality of the study participants was ensured through assigning unique identification numbers to the data. Permission to use the CTC for data collection was obtained from the Director of Hospital Services at Temeke Regional Referral Hospital.

### Trustworthiness and rigour of the data

Several criteria are used to evaluate the trustworthiness of qualitative research, including credibility, dependability and transferability. First, credibility was enhanced by the first author (RJ) spending time in the field to become familiar with the study setting. Second, different perspectives of the researchers involved in the study with various degrees of familiarity with the setting were included. To support dependability of the data, each researcher kept a log of completed activities and data were reviewed by all co-authors.

To support transferability of the data, the transcripts were translated into English and emerging themes were discussed among the research team. This enriched the interpretation of the data through the balance of perspectives representing different backgrounds and qualitative expertise. These measures enhanced the overall credibility and trustworthiness of the representation of participants' views that is presented in these findings. The detailed description of the study context, selection criteria and analytical process along with the use of rich quotations allow readers to judge the dependability of the analysis and transferability of the findings.

Finally, it is important to note the positionality of the principal researcher and any potential bias that may exist. The researcher is an established clinician in Tanzania with a long history of working with paediatric patients and their families, and thus has an 'insider's view' on the benefits and harms that might come to HIV-positive adolescents. This view is advantageous, but also has its limitations. However, the researcher is committed to understanding the ethical challenges that adolescents and their families face in her home country, Tanzania, where prevalence of HIV threatens the lives of young people.<sup>[15]</sup>

## Results

### Demographics of participants

The sample consisted of 16 participants. The majority of the sample were parents ( $n=12$ ), and there were also four non-parent primary caregivers of HIV-positive adolescents. Among the 12 parents, the majority were female ( $n=11$ ), with three non-parent females and one

male represented. Participant ages ranged from 24 to 60 years, with a mean age of 38.2 years. Most of the parents had primary education ( $n=13$ ), while the remaining three had secondary education.

## Qualitative categories

### Parents' and non-parent caregivers' perceptions of ethical issues

Qualitative content analysis resulted in three categories that were perceived as ethical issues by most participants. The categories were: balancing adolescents' autonomy with parents' desire to protect their children; parental dilemmas on disclosure of adolescents' HIV status to adolescents and others; and parental reasons for delayed disclosure.

### Balancing adolescents' autonomy with parents' desire to protect their children

Most participants reported that they did not give their adolescents the freedom to decide for themselves regarding their HIV care. Reasons for their reluctance were the following: the perception that adolescents had insufficient maturity and life experience to make sensitive and consequential decisions; and the economic and emotional support needed by their adolescents. As one participant said:

'I am a mother of two girls who are both living with HIV infection. I checked them when they were young and [they] lacked decision making ability; hence I did not involve them in decision to test and enrol them to care.' (Parent #13)

Participants were also worried about the economic and emotional support available to their adolescent and that because of this, the adolescent should not make their own decisions. This concern is illustrated by the following:

'I think it is not right for an adolescent to make his own decision because he is still dependent on parents, so he has no freedom yet. He was started on HIV care by his parents so it is better he continues with medication until he becomes independent and when a child is under [their] parent's control, he will be getting care and emotional support.' (Parent #1)

Parents and non-parent primary caregivers also did not trust adolescents to decide appropriately without their supervision. This was noted by a parent saying the following:

'Frankly speaking, I would never let the child have [the] freedom to make decision because I have come this far in her care, I cannot let her make [a] stupid decision like foregoing medicine even become pregnant before finishing her studies.' (Parent #4)

### Parental dilemmas on disclosure of adolescents' HIV status to adolescents and others

Most participants reported hesitancy in disclosure because disclosure can be both beneficial and harmful. Some of the benefits of disclosure mentioned were good adherence to ART and HIV-prevention knowledge. Participants identified the harm that might befall adolescents, such as stigma and discrimination.

### Benefits of early disclosure of HIV status to adolescents and others

Participants reported that adherence to ART is not affected by enrolment in the CTC but rather by family unity, especially for families

with more than one individual living with HIV infection and where they all know their HIV infection status. This is signified by the following quotes that speak to the important role of families living with HIV:

'We do remind one another to take medicine and [of the] appointment date. My first son never took his medicine seriously and he ended up dying, the second son took that as a lesson.' (Parent #10)

'We are all taking medication and it helps us remind one another. No one discriminates or abuse one another because we are all the same.' (Parent #11)

### Disclosure can help adolescents to acquire HIV knowledge and prevent its spread

Participants indicated that adolescents who knew their HIV status very early were counselled, taught about how to live while taking ART, and were able to adapt to living with the disease. As noted by participants below, early disclosure of HIV status is important for the long-term health of the adolescent.

'Disclosure is important so that once the adolescent understands, they can adapt to live with HIV infections. Since my daughter begun medications, she is healthy.' (Parent #8)

'When I am not around, her father will guide her, but in the past I could not manage to travel, I had to travel with the child even if she is studying.' (Parent #9)

### Lack of disclosure may result in poor knowledge among adolescents on how to prevent HIV

Delayed disclosure of HIV status to HIV-infected adolescents was perceived as leading to lack of awareness and poor knowledge on HIV prevention in others. Here, parents noted that discussions on HIV were not a priority among their adolescents. For example, a participant said:

'Adolescents are using contraceptive to avoid pregnancy, but they do not talk about HIV infection or reinfection ... The issue of HIV is not a priority to people. As s/he knows if s/he is infected [they] will take medication. This is very challenging in the streets ... adolescents' HIV awareness is very little.' (Parent #9)

'I was not given the explicit explanation that I must test [for] HIV. In the past when you go to the clinic, they just asked you: do you feel like testing for HIV? You see, by then we had no proper knowledge that as [an] HIV-infected woman [you] can deliver [an] uninfected baby. By then we had not been educated on that. I was hurt by the care providers who couldn't educate us properly.' (Parent #5)

### Stigma and discrimination facing adolescents living with HIV

Some participants reported stigma and discrimination towards adolescents living with HIV when their status is known to others in their school and community. This can bring about disruptions in the adolescent's life, causing psychological harm. One participant said:

'I have to transfer my daughter to another school. The former school could not accept her due to her HIV infection. I argued with [the] school administration that she is in Form Three now, don't you see that if we transfer her to another school she will have been disrupted psychologically? They answered me that they are unable to take care of these children, you see.' (Parent #5)

Another participant also mentioned the fear of stigma and being secretive about their HIV status as noted below:

'The challenge is fear of stigma from the community surrounding us because everyone accepts HIV infection as they know it. That's why you decide not to tell. It is a secret to me and my teen.' (Parent #3)

### Reasons for lack of or delayed disclosure from parents' perspective

Reasons for delay in disclosure of HIV status were given as: fear of being judged; fear of being rejected by their children; and fear of causing distress to their children.

One participant said:

'I waited until he was 12, when he refused to take medicines. He was saying: I can't take it, I am done with this, unless you tell me the reason I am taking medicine daily.' (Parent #16)

In a similar way, another participant raised concerns about being judged. Here the participant spoke of 'being asked questions that will hurt you'. This participant went on to say, 'In the past the mass media used to say that if you are HIV infected it means you committed adultery...' (Parent #13)

Another participant feared that a delay in taking one's medicine would be harmful as noted below:

'First I felt sorry to tell him as I didn't know what would be his reaction considering he is still young but knowledgeable. He may be worried if I tell him... But I warned him that you should never miss your medicines even a single day.' (Parent #6)

Some participants reported the difficulty in knowing that they had infected their child with HIV. For example, one participant said that 'it is difficult to accept that I have infected him with HIV as a parent.' (Parent #10)

Another participant blamed nurses for respecting their autonomy to forego antenatal HIV testing rather than enforcing testing for the benefit of their unborn babies, as reported by the quote below:

'I felt very bad with deep pain in my heart till today. I would have checked [my] HIV [status] during antenatal clinic and prevented my daughter from [acquiring] HIV infection. I also blame nurses in [the] antenatal clinic because they would have forced me to check [my] HIV [status] for the benefit of my unborn baby rather than just accepting my refusal not to check HIV.' (Parent #15)

## Discussion

Striking a balance between adolescents' autonomy to make their own decisions and the protective nature of parents and non-parent caregivers, who want to avoid any type of harm to their children, raises ethical concerns in the care and treatment of HIV-infected adolescents.<sup>[16]</sup> The extent to which adolescents possess the decisional capacity necessary to meaningfully participate in their medical care is an important issue for all minors and especially those with chronic illnesses such as HIV.<sup>[16]</sup> There were three important findings from this study. First, parents and non-parent caregivers of HIV-infected adolescents felt as though adolescents do not have the capacity to decide their individual HIV treatment and care. Therefore, parents and non-parent caregivers often made HIV-related care decisions for their adolescents without involving them. Second, disclosure of HIV status and determining when this information should be disclosed to the adolescent or others remains an ethical conundrum for parents and non-parent caregivers. Third, parental guilt was an important finding

in the study, especially for those parents who were also HIV-positive and had transmitted the virus to their child.

What is the role of adolescents in their care and treatment, specifically when they have a chronic and potentially deadly illness such as HIV? This question continues to raise ethical questions on when minors have the capacity to make their own decisions when there is no universal agreement on an age at which they are deemed competent and it may vary by cultural contexts.<sup>[17]</sup> Tanzania is no exception, as the guidelines suggest that parental authority is important in adolescent HIV care.<sup>[18]</sup> Findings from the present study revealed that parents did not feel comfortable letting their adolescent have the freedom to decide about their HIV care and treatment for various reasons. Sometimes, this had to do with issues of trust, other times it had to do with economic or emotional concerns. Parents also feared that their adolescent might not adhere to ART, which is very important for their survival and long-term health and well-being. It is understandable that a parent would worry and want the best health outcomes for their adolescent; however, limiting the involvement of adolescents in their HIV care and treatment may also be harmful. Ethically respecting adolescents and listening to their worries and fears is just as important as the respect clinicians give to parents. Our findings support the work of Hartman,<sup>[19]</sup> who found that physicians will ask parental consent despite adolescents' capacity to decide on their own care.

Interestingly, the 2019 Tanzanian National Guidelines for HIV and AIDS management in the country outline special considerations for adolescents. Indeed, one of the issues is involving adolescents in the planning of their treatment and support of their decisions and encouraging them to reach out with health-related questions and concerns.<sup>[20]</sup> This statement reflects the importance of their growing autonomy and treating them in a fair and just manner by making sure that they have access to supportive systems. Many adolescents have the maturity to make difficult decisions related to their health and well-being and have a growing capacity to understand, reason and make judgements and choices that can have a long-term impact on their lives.<sup>[17]</sup>

Participants in this study also felt that adolescents should not decide for themselves because they lack economic freedom and they are dependent on their parents for economic support. This is supported by other studies.<sup>[4,21]</sup> Moreover, adolescents living in families where an adult is also on ART had better adherence to their medicine regimen. This is most likely because there is emotional support from the adult on ART<sup>[22]</sup> and the adult caregiver also believed in the prescribed HIV medications, which ultimately improved adherence to treatment.<sup>[23]</sup>

Disclosure of an adolescent's HIV status to the affected adolescent is a critical step in HIV care and treatment of this population group.<sup>[24]</sup> In fact, the World Health Organization suggests that disclosure of perinatal HIV status should be known to children by the age of 12.<sup>[25]</sup> Some participants in the current study saw HIV disclosure to adolescents as positive because it could prevent the spread of HIV from adolescents living with HIV to others. This was especially important if adolescents became sexually active before they were informed about their HIV status. At the CTC, HIV-infected adolescents are counselled about sexual partners and are encouraged to abstain or use condoms to prevent secondary HIV infection. If, however, a parent has not disclosed the adolescent's



HIV status, this type of information may be confusing for the adolescent and also place the clinician in a difficult position in knowing what type of information to share and when. Participants further acknowledged that timely disclosure enhances adherence to ART, but fear of rejection from their adolescent peers, feelings of guilt and reluctance about causing distress to their children made them hesitant to disclose HIV infection status to their adolescents. Moreover, they were concerned about accidental disclosure and the harm that might follow. The findings are similar to other studies conducted in different populations, including families and communities<sup>[26-29]</sup> where disclosure was delayed. Future research should examine those factors that influence timely disclosure to adolescents in Tanzania's health clinics and its emotional consequences, as well as how clinicians and the community can support parents to mitigate their fears and concerns.

Finally, some participants who were biological mothers regretted not checking their HIV status through antenatal programmes that would have prevented transmission of HIV to their unborn children. This lack of knowledge was perceived as 'fuel' that spread the disease. There were also concerns from mothers that nurses should not simply respect patients' autonomy when the life of unborn children may be at risk for HIV. Nurses and other healthcare providers are taught to respect patients when they refuse care or treatment, such as HIV tests, that might be beneficial; and there are times when patients refuse lifesaving measures. It is not clear from the data what specific conversations took place between participants in antenatal programmes and the nurses or physicians in those clinics. Future research should better understand the types of conversations surrounding HIV transmission and how nurses introduce these discussions with their patients. It should also address what healthcare workers should do when a patient refuses HIV information.

## Limitations

There were several limitations associated with this study. First, the study interviewed those parents and non-parent primary caregivers who agreed to participate in the study. Parents and caregivers who chose not to participate in the research may have had different views and experiences with their adolescents that are not reflected in our study sample. Second, the study was conducted in one HIV CTC in a major city in Tanzania. Parental views are needed from other regions of Tanzania to identify similarities and differences that may exist. Third, although qualitative data provide in-depth and rich information, it would also be important to quantitatively capture some of the issues identified in the current study and their relationship with health-related outcomes for HIV-positive adolescents and their families.

## Conclusion

The majority of participants in our study perceived that parental authority should override adolescents' autonomy in HIV care and treatment. Although parents might perceive this to be advantageous to the adolescent, it also has the potential for physical and emotional harm. Disclosure of HIV status to adolescents also continues to raise ethical challenges for parents, and future research is needed to better understand these concerns in low- to-middle income countries and the factors that might drive these decisions. Delays in disclosure often occurred because parents felt guilty, and because they had fears of rejection by their adolescents. More work is needed

to educate parents in Tanzania on the growth and development of adolescents and their right to participate in decision-making and the supportive systems needed to help adolescents and their families. Early disclosure is very important to avoid harm to adolescents, to educate them on living with a chronic disease, and to help them achieve their life goals as they mature into adulthood.

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