“I have grown up controlling myself a lot.” Fear and misconceptions about sex among adolescents vertically-infected with HIV in Tanzania

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Abstract: With increased access to HIV treatment throughout Africa, a generation of HIV positive children is now transitioning to adulthood while living with a chronic condition requiring lifelong medication, which can amplify the anxieties of adolescence. This qualitative study explored how adolescents in Tanzania with HIV experience their nascent sexuality, as part of an evaluation of a home-based care programme. We interviewed 14 adolescents aged 15–19 who had acquired HIV perinatally, 10 of their parents or other primary caregivers, and 12 volunteer home-based care providers who provided support, practical advice, and referrals to clinical services. Adolescents expressed unease about their sexuality, fearing that sex and relationships were inappropriate and hazardous, given their HIV status. They worried about having to disclose their status to partners, the risks of infecting others and for their own health. Thus, many anticipated postponing or avoiding sex indefinitely. Caregivers and home-based care providers reinforced negative views of sexual activity, partly due to prevailing misconceptions about the harmful effects of sex with HIV. The adolescents had restricted access to accurate information, appropriate guidance, or comprehensive reproductive health services and were likely to experience significant unmet need as they initiated sexual relationships. Care programmes could help to reduce this gap by facilitating open communication about sexuality between adolescents and their caregivers, providers, and HIV-positive peers. © 2013 Reproductive Health Matters

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Over the last decade, availability of antiretroviral therapy has increased rapidly throughout Africa, with the result that children who were vertically infected with HIV survive to young adulthood. These adolescents can expect to live long, productive and healthy lives provided they continue to adhere to treatment. They will also comprise a growing proportion of people living with HIV in sub-Saharan Africa due to the region’s young age structure and scale-up of interventions to prevent maternal-to-child transmission.1,2

Following improvements in survival, attention has now shifted to how vertically-infected youth experience the transition to adulthood,3,4 with particular focus on their sexual health and behaviour.5–7 This follows research demonstrating that HIV can exacerbate adolescents’ anxieties and vulnerabilities during sexual development for both biomedical and psychosocial reasons.8,9 For example, physical and cognitive delays have been associated with depression,10 low self-esteem and poor body image,11 while the knowledge of living with an incurable infectious disease complicates young people’s attempts to initiate relationships and negotiate condom use through the fear of exposing their HIV status.12

Data on sexual behaviour among HIV-positive adolescents remain limited, and few studies disaggregate their findings by age so that adolescents (10–19) can be compared to older youth (15–24). Some studies have found delayed sexual debut among vertically-infected adolescents,13 while others have reported similar rates of sexual activity among both HIV-infected and uninfected young people and comparable unmet need for contraception and prevention of sexually-transmitted...
infections. Findings on use of contraception are also mixed. Two studies from the US and Uganda found HIV-positive youth were more likely to use contraception, particularly condoms, than those who were either HIV-negative or unaware of their status. For example, in the US study, 94% of sexually active female adolescents aged 13–18 reported use of an effective modern method of contraception compared with 89% of matched respondents. Similarly, the Ugandan study compared surveys of adolescents 15–19, finding that among those who knew they were HIV-positive, 49.6% reported ever-use of contraception and 39.3% current use of condoms. Among those who did not know their status, only 17.0% had used contraception and 11.1% were using condoms.

On the other hand, in a prospective cohort study of 15–24 year olds from Uganda, 34% of sexually active youth with HIV reported contraceptive use compared to 59% of uninfected respondents. When asked about condoms, 24% of HIV-positive youth reported consistent use compared to 38% of the HIV-negative group. The authors concluded that using protection might be more difficult for adolescents with HIV, particularly if they had received counselling messages that did not support or empower them to negotiate with partners.

Recent qualitative studies exploring adolescents’ experience of living with HIV in sub-Saharan Africa show vertically-infected adolescents to be ill at ease in discussing sexuality, preoccupied with secrecy around HIV, and struggling with disclosure to partners. Relationships with parents were often strained, and where parents were themselves HIV-positive, their own emotions restricted their ability to help children navigate the start of their sexual lives. As with other adolescents, those living with HIV had few sources of reliable information on topics related to sex, often relying on peers. Nonetheless, adolescents generally demonstrated a positive outlook, and expected to have sexual relationships and children in future. How adolescents grapple with their nascent sexuality and HIV status may have implications for their subsequent attitudes to sex, risk behaviour, health, and well-being. To explore these relationships, we conducted qualitative research into the perceptions and experiences of vertically-infected adolescents aged 15–19 years old related to sex, relationships and health.

**Study setting and methods**

This was a qualitative study conducted as part of broader research assessing a home-based care programme’s effectiveness in meeting the needs of HIV-positive youth (15–24) in Tanzania. Since 1984, Pathfinder International has been implementing community-based care for families affected by HIV. Through the Tutunzane II programme (“Let’s take care of one another” in Swahili) approximately 1,200 volunteers have been trained to visit households identified through local HIV testing and treatment services. These care providers offer psychosocial support, make referrals to clinical services, and encourage HIV testing among family members. They also give practical advice on nutrition, HIV prevention, and caring for people with HIV. In some locations, the programme has introduced reproductive health and family planning services, including community-based distribution of contraceptives. The programme was not originally designed for young people, and in 2011 just 5% of those enrolled were aged 15–24, despite the fact that 41% of people living with HIV in Tanzania fall into this age range.

Our study focused on adolescents aged 15–19 who were vertically infected with HIV and have been on treatment most of their lives. Little is known about HIV-positive adolescents’ perceptions of sexuality, their ability to access sexual health information and services, and their interpretation of HIV prevention messages. We aimed to better understand the needs and experiences of this group within the context of the home-based care programme, to help to improve existing services.

We interviewed 14 adolescents, 10 family members who served as primary caregivers, and 12 home-based care providers between January and March 2011 in Dar es Salaam and Tanga, a coastal fishing community located in the north of the country. These sites were selected to reflect rural-urban differences and religious diversity (predominantly Christian in Dar es Salaam and
Muslim in Tanga). First, we conducted focus group discussions with the home-based care providers to identify those with experience of working with adolescents within the programme. Discussions provided an overview of the key challenges of working with adolescents with HIV and were used to identify topics for inclusion in interview guides.

The programme providers then recruited adolescents with whom they worked into the study. Eligibility criteria included knowing their own HIV status, enrolment in home-based care, and willingness to participate. For adolescents under 18, permission was first obtained from a parent or guardian. Four fieldworkers (two male and two female) conducted data collection and were matched by sex to adolescents. Fieldworkers were experienced social science researchers without links to the home-based care programme and arranged interviews in private locations at times convenient to respondents, emphasising the confidential nature of the interview. Ethical approval was obtained from the London School of Hygiene and Tropical Medicine and the Tanzanian National Institute of Medical Research.

In-depth interviews explored life events, living with HIV, and issues related to physical development and sexual health. A short, five-question “secret ballot” followed interviews, covering sexual debut, number of partners, condom use, other contraceptive use and disclosure of HIV status to most recent sexual partner. The ballot was self-completed and returned in a sealed envelope, linked to the participant by interview number.

Following the interview, adolescents could nominate a caregiver from their household, who was separately approached for interview and asked about caring for a vertically-infected adolescent, and how they addressed topics related to sexuality and reproduction. The home-based care providers who worked with adolescents were also interviewed about their provision of information and counselling on sex and reproductive health. Adolescents were compensated with a small food package containing flour, sugar and oil, and all participants received a drink and snack.

Interviews were conducted in Swahili and recorded, transcribed, and translated into English by field workers. Transcripts were entered into NVIVO 8 software and a coding framework developed by the first two authors following familiarisation with the data. The framework identified broad themes reflecting the objectives of the study as well as those emerging iteratively. During content analysis, we compared data from adolescents, caregivers and providers, and also analysed transcripts of adolescents together with those of their caregivers to identify household-level experiences. The small number of adolescents who met eligibility criteria precluded meaningful comparisons by sex or study site; overall, however, interviews with girls tended to be longer and more revealing of personal feelings while boys framed their narratives as chronologies of specific life events.

The study had several limitations. We conducted only one interview with each adolescent, which did not provide enough time for fieldworkers to build rapport with them, increasing the possibility that many adolescents expressed views they considered to be socially desirable. It is also possible they believed their responses might affect their relationship with the home-based care programme, although we were careful to stress the independent nature of the research and fieldworkers did not travel in project vehicles or accompany staff.

Findings

We recruited five girls and nine boys aged 15–19, though one girl was found to be 14 after completion of the interview. Most (10) were 15 or 16 years old. All lived at home with relatives, although not necessarily their parents. All five girls were attending school, while four boys were in school, three had left following primary school, one had completed secondary school and one had withdrawn due to acute tuberculosis. All adolescents had been referred to the home-based care programme through clinical services or by a provider noticing their illness when visiting another member of the household. Twelve were taking antiretrovirals; one boy and one girl reported CD4 counts higher than the threshold for initiating treatment.

Among the ten caregivers, there were seven mothers, one grandmother, one great aunt and one father. Based on interviews with caregivers and providers, we believe all the adolescents had contracted HIV vertically, although at least three appear to have been given misleading information by family members and believed they had become infected through casual contact, such as sharing chewing gum or nail clippers, or assumed they had received an infected blood transfusion. Interviews addressed broader aspects of living with HIV before turning to more sensitive issues.
Adolescents were hesitant about discussing sexual matters, avoiding direct questions. This reluctance appeared to go beyond shyness and embarrassment, indicating pervasive anxiety and a sense that sex and relationships were inappropriate and potentially hazardous for them given their HIV status.

Within our sample, 12 respondents indicated no prior sexual experience, one did not answer related questions and one boy reported having had sexual intercourse with one partner, to whom he had not disclosed his status, and that he had not used a condom or other form of contraception at last sex.

To highlight adolescents’ own interpretation of their experiences, we draw heavily on excerpts from their interviews. As noted by others, adolescents are often treated as subjects of research and objects of interventions rather than as “a vital source of knowledge and information about what it means to be a young person growing up with HIV.”

We tried to avoid this mistake.

Postponing sexuality

Early in the interviews, adolescents often claimed they were too young to think about sex, or had not yet “reached” that stage of life. This did not differ by age, with the 18- and 19-year-old respondents just as likely to express negative feelings as those aged 15; indeed, younger adolescents appeared less fearful of infecting others, although this could be because they had not yet had any relationships.

Interviewer: When did you start getting information on relationships?
Respondent: Oh! I have not started…
Interviewer: Have you talked to your parents or any other adult person about relationships/love affairs?
Respondent: No. I am not prepared for that…
Interviewer: What do you think about getting information on family planning?
Respondent: I am not prepared for that. I will seek this information when I’ll have settled down and got married. Not at present… (Male, 18, Tanga)

Avoiding sexual topics and relationships appeared to be strategies for preventing uncomfortable feelings. Although sex was seen as a difficult topic for any adolescent, participants discussed self-restraint as an integral part of living with HIV.

“Truly there are many temptations for any youth. There is a time one feels like having sex with the opposite sex. However, for me, I have tried to make myself busy with something whenever I have felt that urge. Perhaps I would take a book and read it or I would do some writing. After that I would sleep, after which that urge will have disappeared… I have grown up controlling myself a lot.” (Male, 15, Dar es Salaam)

“I have been loved by a certain girl, but because I know how I am [HIV-positive] I kept postponing giving her my love. Since she didn’t get [understand] me I broke up with her. Later I got to love [another] one very much, but I don’t want to make love to her. We have just remained friends.” (Male, 19, Tanga)

Adolescents’ descriptions of feeling “unprepared” reflected adults’ perceptions of them. Caregivers and the home-based care providers found it difficult to reconcile adolescents’ sexuality with their HIV status. Both groups felt uncertain about acceptable timing for introducing sex education, broaching the topic only when they believed adolescents to have already initiated sexual activity, and emphasising its negative consequences. Caregivers, who were primarily mothers, emphasised that their children were still too young for sexual information and worried about causing them additional emotional distress on top of HIV, while providers felt responsible for preventing further transmission.

Interviewer: Aren’t you taught even at school?
Respondent: Mmmh, at school, a teacher may come and just mention a bit but not in much detail, because that is not a proper subject in the syllabus… Truly, I don’t want to know such information… I just don’t want to know… (Female, 18, Tanga)
periods. She is still childish, which makes me wonder – she has not changed.

Interviewer: Have you, as a mother, talked to your daughter about relationships, sex and love?

Respondent: Yes. I do tell her. There was a day she came back from school and said that she had met a “Fataki” [older man seeking a relationship with young women] who has offered her a plate of chips. I tell her that she should not involve herself with such people as they will just waste her time. (Mother of female, 14, Dar es Salaam)

“The challenges we meet, as I have said the issue of love has taken a very big place. You find a person such people as they will just waste her time. I tell her that she should not involve herself with young women who has offered her a plate of chips. a came back from school and said that she had met

be

danger of getting new infections. So I told her to be

he/she to do so while s/he is only 15… We call that age dangerous… I mean it is the age of much desire and lust. There are a lot of temptations, you see? So many youth spread HIV at this age”. (Male provider, Tanga)

Narratives of adolescents, caregivers and providers all highlighted judgmental attitudes toward sex. This likely reflected disapproval of early sexual activity in general, but also highlighted concerns that HIV-infected adolescents could be particularly vulnerable and needed to safeguard their health:

“This one has now reached the adolescent stage. It is a challenge. When I see her talking to boys I normally discourage her and tell her that she should be more careful as her health status isn’t that good. She agrees with me though she makes excuses such as that those are just her school-mates.” (Grandmother of female, 16, Tanga)

“We just sit around and talk casually, with mother reminding me of my health status. She tells me not to get too close to boys… I think she means I should not be too friendly to them – not closer than the ordinary kind of friendliness… One should not be too close to one another like engaged people are, something like that.” (Female, 15, Dar es Salaam)

Several caregivers believed people with HIV should never engage in sex. The mother of the 15-year old girl quoted above subsequently told her daughter that sex should be avoided until a cure for HIV becomes available:

“I talked to her and told her that she was now a grown up woman, that she could get pregnant if she ‘played’ with men, that also there was some danger of getting new infections. So I told her to be ‘cool’ – maybe a cure could be found, that after

she was fully grown up she might even get married, get children and all that stuff… I have been drumming into her head that, ‘it is dangerous to run around with boys now that you have grown up. You should guard yourself as you know that you are already an HIV-positive case’. (Mother of female, 15, Dar es Salaam)

On the other hand, parents were willing to concede that when adolescents did begin to have sex, they should know about condoms. According to the daughter above, her mother had discussed condoms with her and one of her friends. Similarly, the male caregiver below reported having talked about condoms with his son but also felt sex was unacceptable for people living with HIV:

“I don’t go longer than three days before I hammer into him the seriousness of these issues. I try to instill into his senses that his condition doesn’t allow him to have sex with any girl. It is not permissible… If, say, we see a girl pass by I call his attention to her. He usually laughs it off and says that he is not interested in girls. I reinforce that statement of his and tell him to stop right there.” (Father of male, 15, Dar es Salaam)

Parental attitudes thus proved contradictory, and in some cases gave the message that rather than simply postpone sex, adolescents with HIV should plan to avoid it throughout their lives. This may have contributed to adolescents’ denial of their sexual feelings.

Sex, risk and health

When adolescents did acknowledge having sexual feelings, their first concern was whether and how to disclose their status to a potential partner, and what response they would receive. Most assumed disclosure would inevitably lead to rejection and discrimination, and these were considered the most threatening risks associated with sex:

“The challenges that we get, mostly is when a person recognises that you are HIV positive, since other people are not understanding, you will also have that kind of stigmatisation… and secondly it is the men, men who are making advances towards you, when you refuse, he does not accept; he will be disturbing [you]. So the challenge is twice – from people and from men.” (Female, 18, Tanga)

“I have not thought about it [relationships/marriage] yet…You might be afraid of infecting
the person you live with. Otherwise if you tell someone he may reject you… So you count yourself useless. It is better to stay single.” (Female, 15, Dar es Salaam)

There were also fears about transmitting HIV, and a strong sense that they should not be responsible for someone else’s infection. Adolescents discussed feeling overwhelmed by the implications of infecting others:

“I shall be destroying a girl’s life if I were to look for one now.” (Male, 15, Dar es Salaam)

Respondent: … so many men are wooing you, you need be careful; and since men began following me, I have never come to an understanding with any.

Interviewer: Why? Don’t you have feelings?

Respondent: I have; but it is just… Well, to infect another person, I don’t think it’s fair… You might not infect him in the first place, but it might reach a time he will contract it.” (Female, 18, Tanga)

“It is hard for me because I know my health status and I know how it has made me unhappy, uneasy and uncomfortable. I would not like to ‘give it’ to another person who might be well. I don’t like it at all.” (Male, 18, Tanga)

There were also concerns about their own health. Respondents listed numerous admonitions they’d received since childhood on nutrition, treatment adherence, preventing and treating opportunistic infections, and taking adequate rest. Interestingly, avoiding sexual activity appeared to be one of these explicit health messages, received from clinics, providers, and parents:

“Truly, love, I have never done it. Not even once. I just won’t do it for I know my weakness. I can’t do it. What to do? They tell us to use some protective gear if you want to make love so that you do not get weaker. This we are told at the hospital. That is what they tell us.” (Male, 16, Tanga)

“There are times that they tell me that I should not do such a thing, at the hospital. Sometimes they gather us children together and tell us not to do so… ‘Don’t do this thing – I mean this love thing. They aren’t good things.’ They prohibit such acts.” (Male, 15, Dar es Salaam)

We found the perception that sex can weaken HIV-positive people and expedite progression to AIDS to be common among respondents. While the use of “protective gear” could mitigate this harm, abstinence was considered safer. Parents and providers confirmed that part of their motivation for discouraging sexual activity among young people was to preserve their health:

“… once a person who is living with HIV has sexual intercourse… they should have sexual intercourse with condoms, and at [rare] intervals, not as pleasure, say, on a daily basis, no. This is simply because the sexual act exhausts and it’s tiring.” (Mother of male, 15, Tanga)

“I’m trying my level best to create awareness that if one has sex frequently, it leads to deterioration of health, unless you use protective gear.” (Female provider, Dar es Salaam)

“To try and control their urge for sex we advise the youth to look for alternatives to sex, things like physical exercises, games… What they should do is avoid sex, for surely sexual intercourse weakens the body’s CD4, but then at their age, they need sex. To abstain from it is surely hard. So to help them would mean to look for other ways of convincing them to see sex as poison… So I try to convince her to reduce her frequency of sexual intercourse because it… shortens one’s life span.” (Female provider, Tanga)

Wishing to avoid sex thus became a rational response on the part of the adolescents, part of appropriate self-care alongside eating fresh fruit and vegetables or adhering to medication.

Expectations for the future

Despite current anxieties, many vertically-infected adolescents believed it possible for them to marry and start families in future. Six respondents stated they would like to find a life partner and start a family once they had completed their education or fulfilled other ambitions.

“We were taught that one can get married and get a child who is HIV-free. So God willing when I will have got some employment I can get married. I wouldn’t like to get married before I get a job… I would like to have two children…” (Female, 16, Tanga)

“I would like to have my own family but I do not want to have such thoughts now, education first.” (Male, 15, Tanga)

Four expressed negative sentiments toward marriage, but this appeared to be related to having
witnessed abusive relationships or being worried about hiding their status:

“I saw the [violence] that one woman who had got married was getting. I said to hell with getting married… One woman in our neighborhood used to be beaten every day. It put me off and I vowed that I shall never get married.” (Female, 15, Dar es Salaam)

“The thing that prohibits me from getting married is mainly this disease I have contracted. That is what I think, however, I’m not sure though… but I think if I want to be married, I can; and maybe I wouldn’t reveal [HIV] to the respective man, but how will I be able to use my medicine, as he will see me, no? Definitely, he’ll see the medicine.” (Female, 18, Tanga)

**Interviewer:** Haven’t you received information that a youth like you is capable of getting married and living a normal married life?

**Respondent:** I understand that is possible but I don’t see myself living a contented life in marriage like the other ordinary people do.

**Interviewer:** So you neither have dreams of getting married nor of bringing children into the world?

**Respondent:** Mmmmh. No.” (Male, 15, Dar es Salaam)

Yet many providers encouraged young people to think optimistically about the future. Adolescents were able to recall information from providers on prevention of HIV transmission within marriage, during pregnancy and childbirth. Providers also described how they viewed their role as bolstering the self-esteem of people living with HIV, including instilling confidence that they can live a normal life like anyone else:

“First of all, a youth living with HIV should be encouraged and shown that s/he is like any other person and should be involved in all matters of the society around him/her. S/he should be listened to: If one for example says that s/he would like to get married, s/he should be counselled about it.” (Female provider, Tanga)

Yet the same providers who encouraged adolescents about their future were those who believed sexual activity caused weakness and damaged health. Receiving mixed messages may have contributed to adolescents’ belief that they should postpone sexual relationships to an unspecified time in future, when they would be able to analyse their situation and take their own decisions:

“I have decided not to engage in any sex until I complete school. Then I shall know what to do…” (Female, 15, Dar es Salaam)

**Discussion and recommendations**

This study adds to a growing body of evidence that as children with HIV transition to adulthood, their sexual and reproductive health needs remain neglected. As in other research, the adolescents we interviewed reported feeling awkward about their sexuality, unwilling to discuss sex with adults, and discouraged from sexual activity. Caregivers and providers also felt ill equipped to counsel adolescents.

While difficulties surrounding sexual communication with young people are well documented we found that HIV further complicates barriers to open communication, particularly in the presence of the prevailing belief that sex is “dangerous” and accelerates progression to AIDS. It is unclear why so many family members and home-based care providers reinforced this inaccurate information, but we hypothesise that the risk of re-infection through unprotected sex has come to be understood to mean that sexual activity itself causes weakness, rather than further exposure to HIV.

A study of sexual behaviour following treatment initiation among HIV-positive adults in Uganda found similar fears.

There have been many calls for strengthening reproductive health services for people living with HIV as part of wider rights-based approaches. Most recommendations emphasise the importance of providing psychosocial support and clear, age-appropriate information, and access to contraception and condoms. The pervasiveness of misconceptions and reluctance to accept adolescents’ sexuality in our study, however, suggests it might prove difficult to expand service provision without first correcting factual inaccuracies and tackling judgmental attitudes toward HIV-positive people’s sexual activity. Improving the home-based care training package could be a useful first step, including directly addressing providers’ incorrect beliefs about sex-related health risks and ensuring they understand their role to be neutral conduits of information and advice.

Among caregivers, we found a desire to help adolescents confront the challenges of sexuality,
but uncertainty on how to do so, which likely contributed to their sometimes contradictory messages. Another programmatic option, therefore, would be to support caregivers in talking to young people about sex and adapting existing interventions to improve the quality of parent-child sexual communication. In Mexico, for example, a randomised, controlled trial found that running workshops to teach parents communication skills, including how to listen to their children, created opportunities to discuss sexual risks and manage discomfort, resulted in a significant increase in conversations about sex and protection compared to a control group.38 In South Africa, participatory workshops helped parents and guardians develop their own strategies for addressing sex and HIV with young people, resulting in more frequent efforts to communicate and improved messages.26 In our Tanzanian context, home-based care providers were assigned to whole households and could potentially bring caregivers and adolescents together to facilitate dialogue about the sexual dimensions of growing up with HIV.

Finally, peer support groups have been shown in other settings to improve confidence and uptake of health services.19,39,40 The use of peer education and group activities could potentially be integrated into home-based care programmes or linked through referrals to widen adolescents’ access to sources of information and support.19

It is not unusual for adolescents to experience anxiety as they come to terms with their sexual feelings and desires, nor for parents and caregivers to respond with discomfort and concern. The presence of HIV may exacerbate both adolescent fears and adult protectiveness, but does not pose an insurmountable barrier to more open communication and providing accurate information. Many challenges remain in meeting the needs of vertically-infected adolescents as they undergo sexual development, initiate sexual activity, form relationships, and take decisions about childbirth. Supporting them through these experiences and the adults who care for them is critical to ensuring a fulfilling future for this growing population of young people.

References


Résumé
Grâce à l'accès élargi au traitement du VIH en Afrique, une génération d’enfants séropositifs entre maintenant dans l’âge adulte tout en vivant avec une affection chronique qui demande une médication tout au long de la vie, ce qui peut amplifier les angoisses de l’adolescence. Cette étude qualitative a demandé comment les adolescents avec le VIH vivent leur sexualité naissante en Tanzanie, dans le cadre de l’évaluation d’un programme de soins à domicile. Nous avons interrogé 14 adolescents âgés de 15 à 19 ans contaminés par le VIH durant la période périnatale, 10 de leurs parents ou autres responsables principaux et 12 bénévoles prestataires de soins à domicile qui leur apportaient un soutien et des conseils pratiques, et les aiguillaient vers des services cliniques. Les adolescents ressentaient un malaise à propos de leur sexualité et craignaient que les rapports sexuels soient inappropriés et risqués, compte tenu de leur séropositivité. Ils appréhendaient de devoir révéler leur statut aux partenaires, s’inquiétaient du risque d’infection et craignaient pour leur propre santé. Beaucoup prévoyaient donc de reporter indéfiniment ou d’éviter les rapports sexuels. Les proches et les prestataires de soins à domicile renforçaient les idées négatives sur l’activité sexuelle, en partie du fait des préjugés dominants sur les conséquences néfastes de la sexualité avec le VIH. Les adolescents disposaient d’un accès restreint à des informations exactes, à des conseils adaptés ou à des services complets de santé génésique et risquaient de connaître d’importants besoins non satisfaits au moment où ils deviendraient sexuellement actifs. Les programmes de soins pourraient combler ces manques en facilitant une communication ouverte sur la sexualité entre les adolescents et les personnes qui s’occupent d’eux, les prestataires de soins et les pairs séropositifs.

Resumen
Con mayor acceso al tratamiento del VIH en toda África, una generación de niños VIH-positivos ahora está pasando a la adultez a la vez que vive con una enfermedad crónica que requiere medicamentos de por vida, lo cual puede amplificar las ansiedades de la adolescencia. En este estudio cualitativo en Tanzania se exploró cómo la adolescencia con VIH experimenta su sexualidad incipiente, como parte de una evaluación de un programa de cuidados domiciliarios. Entrevistamos a 14 adolescentes de 15 a 19 años de edad, que habían adquirido el VIH por transmisión perinatal, 10 de sus padres u otros cuidadores principales y 12 voluntarios proveedores de cuidados domiciliarios, quienes brindaron apoyo, consejos prácticos y referencias a servicios clínicos. Los adolescentes expresaron inquietud respecto a su sexualidad, por temor de que el sexo y las relaciones fueran inapropiados y peligrosos, en vista de su estado de VIH. Se preocupaban por tener que revelar su estado a sus parejas, por los riesgos de infectar a otras personas y por su propia salud. Por ello, muchos de ellos previeron tener que aplazar o evitar las relaciones sexuales por tiempo indefinido. Los cuidadores y prestadores de servicios domiciliarios reforzaron los puntos de vista negativos sobre la actividad sexual, en parte debido a ideas erróneas imperantes respecto a los efectos dañinos de tener sexo con VIH. Los adolescentes tenían acceso limitado a información exacta, orientación correspondiente, o servicios integrales de salud reproductiva y probablemente tenían una importante necesidad insatisfecha según iniciaban sus relaciones sexuales. Los programas de tratamiento del VIH podrían ayudar a llenar esta brecha al facilitar comunicación abierta sobre la sexualidad entre adolescentes y sus cuidadores, prestadores de servicios de salud y pares VIH-positivos.