Experiences of HIV-Positive Adolescents and Young Adults in Care in Soweto, South Africa

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The authors of this qualitative study explored clinic experiences of adolescents and young adults (AYAs) attending HIV treatment at the Perinatal HIV Research Unit, Soweto, South Africa. Focus group discussions were conducted with 18 AYAs to elicit perspectives about the clinic and the staff, ideas for improvements, and opinions about clinic transfer. Three themes emerged: preference for personalized patient–provider relationships, suggestions for clinic improvements, and negative perceptions of transfers to community clinics. The findings provide insight into building youth-friendly HIV treatment services. Further research is needed to understand if negative perceptions of transfers to community clinics will translate into poor retention.

Keywords: adolescents, young adults, HIV, care, South Africa, perinatal transmission
INTRODUCTION

In South Africa, 10.6% of the population is living with HIV infection (Shisana, 2009). Even though HIV prevalence is higher in a few other countries, South Africa has the largest number of people infected, an estimated 5.6 million in 2009 (UNAIDS, 2010). HIV prevalence is highest among people aged 15 to 49 years (17.8%), with adolescents and young adults (AYAs) particularly affected (UNAIDS, 2010). The age range of those considered to be AYAs is variable: authors have used the term to describe the second, third, and occasionally the fourth decades of life (Geiger & Castellino, 2011).

The mode of HIV acquisition differs by region. In high-income countries, most AYAs who acquire HIV are infected through risky sexual behaviour (Department of Health and Human Services, 2011; Dowshen & D’Angelo, 2011). However, data from South Africa show that 62% of HIV-positive AYAs aged 9 to 28 years acquired HIV perinatally (Nglazi et al., 2012), and many are now surviving to adulthood owing to the advent of combination antiretroviral therapy (ART) (Dowshen & D’Angelo, 2011).

Regardless of infection mode, studies in both high- and lower-income countries show that HIV-positive AYAs display suboptimal health behaviors compared with their adult counterparts: they display delays in seeking care, delays in ART initiation, poorer ART adherence, poorer viral suppression rates and lower retention (Minniear et al., 2012; Nachega et al., 2009; Ryscavage, Anderson, Sutton, Reddy, & Taiwo, 2011). Although poorer treatment outcomes imply that AYAs are a vulnerable risk group and support the idea that AYAs require a comprehensive system of care to manage both the medical and psychological needs of HIV (Department of Health and Human Services, 2011), adolescent-specific clinics are rare. AYAs are often treated at either adult or pediatric clinics (Agwu et al., 2012). There, they may receive care from providers who have varied training and experiences with catering for the particular social, educational, psychological, sexual health, and medical needs that arise in this age group—all of which may be influenced by an HIV diagnosis.

Clinic-related factors, including staff attitudes, possibly influence HIV-positive AYAs to initiate and continue ART. In the United States, one study found that behaviorally infected youth aged 12 to 24 years discontinued ART sooner at an adult clinic compared with a pediatric clinic (Agwu et al., 2012). It is possible that pediatric services are more youth-friendly than adult services in terms of relevant staff training, appropriate programs, and lower patient-to-provider ratios (Agwu et al., 2012). Thus far, there is limited information available to understand these kinds of results more deeply; quantitative studies have not identified promoters of and barriers to care and they do not evaluate the effect of clinic structures (Agwu et al.). Little is known about the experiences and expectations regarding care of...
HIV-positive AYAs at HIV clinics and the dearth of qualitative studies addressing perinatally infected AYAs is marked.

To assist with creating a better understanding of the experiences of HIV-positive AYAs in care, we conducted a qualitative study among a South African population of HIV-positive AYAs receiving ART at adult and pediatric clinics. We solicited their opinions on clinic structures, access to ART and other health services, clinical staff–patient communication and relationships, and ideas for clinic improvements. The end goal is to help inform improvements at Soweto clinics so that the clinical, social, and health education needs of HIV-positive AYAs are considered and met effectively as these patients transition to community clinics.

METHOD

Setting

A qualitative study was conducted using focus group discussions from March to July 2012 at the Perinatal HIV Research Unit (PHRU) located at the Chris Hani Baragwanath Hospital in Soweto, South Africa. Soweto is a group of urban townships southwest of Johannesburg, with an estimated population of over 1 million (City of Johannesburg, 2012). The PHRU houses two HIV treatment clinics—one for adults and one for pediatrics—and offers HIV testing and prevention. HIV-positive AYAs are treated at either the adult or pediatric HIV clinic.

In 1996, the adult clinic opened to treat HIV-positive individuals of all age categories, and initially treatment provision was through research studies. After the inception of the pediatric clinic, it narrowed its treatment focus to enroll AYAs and adults. At the time of the study, this clinic employed two physicians, three nurse clinicians and three lay counselors. As of March 2012, the adult HIV clinic had treated 2,186 patients.

The pediatric clinic opened in 2001 to treat infants, children, and adolescents, and by March 2012 had treated 1892 patients. Two physicians, three nurse clinicians, and one lay counselor staffed the pediatric clinic.

At both clinics, treatment has always been free of charge to patients, having been funded initially by clinical trials, by the United States President’s Emergency Plan for AIDS Relief donor funding from 2005, and by the South African government from 2010. At the time of the interviews, these clinics were creating processes to refer patients out to community-level care, necessitated by the end of donor funding.

The nurse clinicians and physicians in both HIV clinics were responsible for diagnosis, treatment and consultation, and they generally followed the national South African guidelines for treatment and monitoring (National
Department of Health South Africa, 2010). Both clinics shared one social worker who was responsible for home visits and counseling for patients and their families.

Participants
Patients were eligible to participate if they were between the ages of 15 and 25 years at the time of study, stated they were HIV-positive, and had received ART at either the PHRU adult or pediatric clinic and were able to provide voluntary written informed consent. If individuals were less than 18 years old, assent with parental consent was required for participation. Participants and parents were each given a one-time transport reimbursement of R50 (approximately US $6).

Ethical and Community Approvals
Ethical approval was obtained from the University of the Witwatersrand Human Ethics Committee. Confidentiality was ensured by deidentifying data; no names were documented on the screening and sociodemographic questionnaire or interview forms.

Prior to study initiation, study aims and procedures were presented to the PHRU adolescent community advisory board who agreed that the chosen themes were relevant, adequate, and appropriate to investigate in the setting.

Data Collection Procedures
Clinic databases identified those who matched study age and treatment criteria. Study representatives recruited by telephone by briefly describing the study purpose and procedures during the phone call. They invited AYAs, and parents if AYAs were less than 18 years old, to receive additional information at a private room in the PHRU. AYAs and parents read informed consent documents, which, among other points, noted that participation in a focus group carried the risk of loss of confidentiality. Study representatives also engaged in a conversation with AYAs and parents to explain the document, answer any questions and gauge understanding.

After voluntary informed consent/assent were signed, interviewers completed a brief structured sociodemographic questionnaire with each participant individually.

The sociodemographic questionnaire collected information about HIV transmission mode, HIV status disclosure, and socioeconomic status. Food security was used as a proxy for socioeconomic status. The nine questions of the food security scale were based on questions about households and adults in the U.S. Household Food Security Survey Module (Bickel, Nord, Price, Hamilton, & Cook, 2000; Carlson, Andrews, & Bickel, 1999). The
questions enquired about the previous month, assessing food security along a range with regard to three main areas: insufficient quality of food, anxiety about food, and insufficient food intake. Adolescents with three or more positive responses were classified as food insecure; those with one or two positive responses were classified as marginally insecure; and those with no positive responses were classified as food secure (Bickel et al., 2000; Jyoti, Frongillo, & Jones, 2005; Winicki & Jemison, 2003).

Focus Group Discussions

Focus groups were conducted to elicit main themes around the topic of clinic experiences for AYAs. The interview guide was piloted with a convenience sample of three AYAs attending the pediatric clinic who volunteered their time and opinions so the interviewers could gauge understanding of the questions and refine the guide. Pilot data were not included in our analysis.

With the finalized question guide, four groups, each consisting of three to seven participants who were purposively sampled, were conducted. Focus groups were composed by clinic and gender: (i) females from the pediatric clinic, (ii) females from the adult clinic, (iii) males from the pediatric clinic, and (iv) a mixed group of males and females from the adult clinic.

Focus group discussions were between 45 and 90 minutes long and were audio-recorded and facilitated by two young, local, and multilingual female interviewers experienced in AYA qualitative research and trained on HIV and treatment issues for adolescents. One facilitator moderated the discussions and the other took notes on the main themes while ensuring that all questions were discussed. An observer noted important nonverbal communication. The focus group discussions were conducted in a mix of English, Zulu, and Sotho, with the facilitator fluent in all three languages. The audio-recorded transcripts were translated into English and transcribed.

Focus Group Discussion Question Content

Focus group discussion questions (Table 1) were based around clinic experiences. Questions elicited the perspectives and experiences of AYAs about their HIV clinic with respect to the clinic staff, appointment procedures, their ideas for improvements, and their opinions about being transitioned to another clinic. Questions were open-ended at first and probed where necessary to generate robust data.

Data Analysis

Sociodemographic data were coded into a Microsoft Excel spreadsheet, and descriptive statistics and frequencies were calculated using Statistical Package for the Social Sciences (SPSS) version 18.0. Focus group discussion transcripts
were hand-coded by a primary investigator using thematic coding. Following
this approach, codes that emerged from the data were analyzed and similar
codes were grouped into themes and sub-themes. Relevant quotations were
selected from the transcripts to exemplify and support the identified themes.

RESULTS

Overall, we identified 186 patients between the ages of 15 and 25 years who
received antiretroviral therapy at either the PHRU adult or pediatric clinic. Of
these 123 AYAs had telephone numbers documented in the database or
medical record and were called. Eighteen participated in the study (15%).
The proportion of those who participated was 11% (5/47) for males, 17%
(13/76) for females, 14% (10/72) for patients receiving treatment from the
pediatric clinic, and 16% (8/51) for patients receiving treatment from the
adult clinic.

Participant characteristics are shown in Table 2. The median age of part-
icipants was 18.5 years [interquartile range (IQR) 17–23 years]. Ten (56%)
were from the pediatric clinic. Eleven (61%) participants indicated that they
had acquired HIV through mother-to-child transmission. It was most com-
mon to have disclosed HIV status to siblings (n = 11, 61%). All participants
indicated that they had disclosed to at least one household member. Thirteen
participants (72%) were classified as food insecure.

Three main themes emerged: (a) personalized and open patient–
provider relationships, (b) suggestions for clinic improvements, and (c)
negative perceptions of being transferred to a different clinic.

Personalized and Open Patient–Provider Relationships

Participants from the adult and pediatric clinics expressed that they had good
relationships with health care providers including the physicians, nurses,
counselors, and the social worker. They perceived relationships as close if

<table>
<thead>
<tr>
<th>TABLE 1 A Summary of Focus Group Discussion Topics and Corresponding Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>What are the good and not-so-good things about the clinic?</td>
</tr>
<tr>
<td>Probes: What do young people think about the physicians/nurses/counselors/social workers/relationship between young patients and staff at the clinic? Can young people talk easily about what they want at the clinic? Why do young people go to the counselor and social worker? Why would they not go? About which topics do the young people usually like to talk with the counselor/social worker?</td>
</tr>
<tr>
<td>What would you change in the clinic and why?</td>
</tr>
<tr>
<td>Probes: Do you have ideas for more services for the teenage patients to support their needs? Do they talk to the young people about sex and contraception (prevention methods)? What can be done better at the clinic? Would you like to change the way the physicians/nurses hold their consultations? Are you happy with the filing room staff, pharmacists, the wait time?</td>
</tr>
<tr>
<td>What happens if you had to go to another clinic? (no probes for this question)</td>
</tr>
</tbody>
</table>

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providers remembered them as individual patients. AYAs also reported that working with confidential and nonjudgmental providers was important to them. When providers were perceived to have these characteristics, the AYAs referred to them as “friends” or “mothers.”

AYA patients said they were able to interact more openly with counselors and social workers when the counseling technique supported AYAs through the process of formulating their own plans. A 16-year-old male from the pediatric clinic expressed that “the social workers they treat you like their child, you cannot point a difference between you and their own child.” A female adolescent aged 17 years pointed out that “My mother she will judge me, she won’t understand at all, so like that is why I think it is better for us to talk to counselors... counselors are there to listen.”

AYA attendees of the pediatric clinic described their physicians as friends and mothers. Open communication was emphasized. One 18-year-old female adolescent said, “I am free when I am with them [physicians and nurses], we talk a lot like friends. I am very open to them, they are also open to me.” Confidentiality was also valued. Another female participant, 16 years old, said, “Whatever we talk about, it will stay between us.”

### Table 2

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Median age, yr (IQR)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinic attendance, n (%)</td>
<td>18.5 (17–23)</td>
</tr>
<tr>
<td>Adult</td>
<td>8 (44%)</td>
</tr>
<tr>
<td>Pediatric</td>
<td>10 (56%)</td>
</tr>
<tr>
<td>Gender, n (%)</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>13 (72%)</td>
</tr>
<tr>
<td>Male</td>
<td>5 (28%)</td>
</tr>
<tr>
<td>HIV infection acquisition, n (%)</td>
<td></td>
</tr>
<tr>
<td>Vertical transmission</td>
<td>11 (61%)</td>
</tr>
<tr>
<td>Heterosexual transmission</td>
<td>4 (22%)</td>
</tr>
<tr>
<td>Unknown</td>
<td>3 (17%)</td>
</tr>
<tr>
<td>People to whom HIV status is disclosed,* n (%)</td>
<td></td>
</tr>
<tr>
<td>Biological mother</td>
<td>8 (44%)</td>
</tr>
<tr>
<td>Biological father</td>
<td>1 (6%)</td>
</tr>
<tr>
<td>Sibling/s</td>
<td>11 (61%)</td>
</tr>
<tr>
<td>Grandparent/s</td>
<td>7 (39%)</td>
</tr>
<tr>
<td>Partner/s</td>
<td>4 (22%)</td>
</tr>
<tr>
<td>Friend/s, teachers</td>
<td>2 (11%)</td>
</tr>
<tr>
<td>Other</td>
<td>7 (39%)</td>
</tr>
<tr>
<td>Food security, n (%)</td>
<td></td>
</tr>
<tr>
<td>Insecure</td>
<td>13 (72%)</td>
</tr>
<tr>
<td>Marginally secure</td>
<td>2 (11%)</td>
</tr>
<tr>
<td>Secure</td>
<td>3 (17%)</td>
</tr>
</tbody>
</table>

*Multiple responses allowed.
Attendees of the adult clinic perceived their physicians in a way that was also clinical, which was both positive in terms of professional provision of medical care and negative in terms of time limitations to discuss nonmedical issues. A female participant aged 24 years said, “The physicians are punctual, supportive and everything, like what they promise you is what you’ll get, you’ll get better.” Three AYAs from the adult clinic perceived that nurses working there were too busy and therefore unwilling to discuss personal issues with patients, advising them only on HIV medication issues.

Even though pediatric-based AYA patients claimed strong relational bonds with the clinical staff, two girls declared that the physicians and nurses can become unfriendly, shout and not attempt to understand them when they confessed that they forgot taking doses of their HIV medication.

Another female participant from the pediatric clinic found it difficult to adjust to new physicians; building up a relationship with new clinic staff was stated as a challenge for AYA patients over and above their medical matters.

Generally, participants agreed that AYA patients can openly talk with providers about everything they come across in life as an adolescent or young adult, but also about issues they encounter as HIV-positive people. Participants expressed feeling at ease when at the clinic because communication with providers was open about issues that they are not comfortable discussing with family members or friends. Specific issues of interest that were mentioned were sex, condom use, romantic relationships, HIV medication difficulties, self-esteem, drug abuse and school problems. One 17-year-old female participant from the pediatric clinic explained tearfully that her counselor was helping her address the low self-esteem arising from the HIV medication side effect of lipodystrophy, which caused her arms and legs to be disproportionately thin in comparison to her body.

I was drinking this other medication, so, like, my arms and my legs, they were very bad. So I couldn’t go to school any more. Like, my friends used to talk bad about my legs and things like that. So I wasn’t strong enough to face up with all those challenges so, like, (sobbing) sorry, so, like, I wasn’t that brave. So I just... the reason why I see counselors—it’s because of those things.

Many participants indicated that they would rather talk to a clinic staff member than to their own mothers, because they felt they received the required support and advice they often “do not find inside the house” (18-year-old young female adult). A female participant aged 17 years said that when “I have problems... I talk to the physicians about basic things which I cannot talk about with my mother.”

AYAs particularly valued physicians who do not “stick to the clinical matters only, they will ask about how is life... they don’t just stick to what is supposed to be done” (17-year-old male patient from the pediatric clinic).
Participants from the adult clinic emphasized to a greater degree their open communication with the social worker and counselors who were praised as being confidential. A 25-year-old female participant from the adult clinic complained that nurses were not always confidential: “They don’t care if there’s other people sitting there. They tell the other nurse what problems they have with you and that’s not nice.”

Suggestions for Clinic Improvements

AYAs voiced their ideas of how to improve the pediatric and adult clinics, which included employing translators to assist during consultations with English-speaking providers for AYAs more comfortable using their mother tongue, improving service provision by accommodating appointment times after school, and executing pill counts to demonstrate adherence in front of the patient.

The prevailing areas of dissatisfaction with service revealed system bottlenecks. Participants suggested that more staff be employed in pharmacy to reduce the waiting time for medication to be dispensed. There was a suggestion that the waiting time for the file at the filing room be reduced. Participants in the adult clinic suggested that the waiting for the nurse to schedule the next appointment date be eliminated by asking the physicians to provide the return date during the consultation.

Two participants from the adult clinic suggested that sanitary facilities be improved and that separate toilets be created for male and female patients.

AYAs suggested more support and information be given to help patients navigate clinic structures for their required service. Other participants made an appeal for material support, for example provision of additional heaters in the waiting hall during cold days and financial support to reimburse poor patients’ transport and food while waiting in the queues. One 17-year-old male participant from the pediatric clinic expressed the desire for differentiated waiting areas for symptomatic and asymptomatic patients. “They can try to separate us... because if we are mixed with the sick ones we end up being sick as well when we come back, no ways no.”

Four participants stated they wanted improvements in their HIV medications to make the pills smaller and have a better flavor.

Suggestions were also made about how to make clinics AYA-friendly. One female participant suggested the development of an information booklet in local languages to provide information about issues such as self-esteem, sex and alcohol use in the context of HIV that may be difficult to discuss with parents and guardians. Another adolescent, an 18-year-old female, desired a booklet for parents to advise them how to interact with their AYA children.
“My mother, in most cases, accompanies me when I come here at the clinic. And my mother can be educated—fine she is educated—but there are some things that she cannot understand. I think that they have to have booklets or something that your parents could read while you see the physician or maybe be involved in activities that can be done maybe based on teenagers, because most of the things we are not talking to our parents about.”

There was a suggestion for creating a space in the clinic for AYA patients to socialize and fetch medication refills. An 18-year-old female participant wanted clinic staff to conduct active case finding of undiagnosed adolescents through HIV testing outreach campaigns at schools during weekdays or at community halls on Saturdays. “There are children at school who are sick [with HIV]. You’ll never know what makes them sick and they also don’t know what’s making them sick. And the child falls sick maybe two or three times in a week. So it could be better if they [clinic staff] come [to the school] so that they’ll know what’s making them sick.”

Negative Perceptions of Being Transferred to a Different Clinic

This theme was discussed in terms of the following subthemes: familiarity with PHRU clinics, stigma at community clinics, and anxiety about medication stock-outs.

The adult clinic participants were unanimous that they would under no circumstances agree to being transferred to a community clinic, although some would agree to transition to another clinic at PHRU. Similarly, all the pediatric clinic participants agreed that they would rather continue to receive treatment at the pediatric HIV clinic than be transferred to another clinic. Eight participants from the pediatric clinic stated that they would under no circumstances agree to be transitioned to a different clinic, even the neighboring adult clinic. They cited relationships with the staff and familiarity with the environment as reasons for this. One female aged 18 years from pediatric clinic said that she “…grew up here and they know you more than where you come from.”

Additionally, three female participants expressed the fear of stigmatization at community clinics. Pediatric clinic AYAs were concerned that community members might discover their HIV status if they were to be seen there. AYAs from adult clinic were also concerned that staff at other community clinics might treat them judgmentally and disrespectfully, similar to the experience of one woman aged 24 years at her community clinic: “I found out about my status when I was pregnant, so the sister that told me that I am HIV positive…she just shouted, calling other sisters telling them that I am pregnant and I am sick and it was so embarrassing.”
Nevertheless, two female participants from the pediatric clinic recognized that because treatment was lifelong, they may well need to adjust to new environments at some time in their life. “The thing is that you know you want to live, you want to get married, have children, so why do you have to bother yourself about what other people say, so I can go to any clinic...because I would know what I went there for [HIV medication]” (18-year-old girl).

Five participants from the adult clinic had concerns over HIV medication stock-outs at other clinics. A female AYA from the adult clinic said, “You will never hear that the medication is finished [at the PHRU] unlike another clinic I know, where you find that on certain days the medication is not there, telling you, you have to come back the following week.”

**DISCUSSION**

This is the first study that documents qualitatively the experiences of South African HIV-positive AYAs in care. Its completion is in time to inform community clinics to implement the lessons learned as patients are being transferred from the donor-funded clinics of PHRU to state community clinics, which was necessitated by the conclusion of donor funding. In our setting, adolescent-specific treatment clinics are non-existent and pediatric HIV clinics are few (Meyers et al., 2007) so our findings can encourage community health clinics to build youth-friendly HIV care. Implied in these findings is a role for the integration of medical and social services.

Indeed, the lessons we learned from our participants are instructive across different settings to a wide audience, including policy makers, clinic administrators, and health care professionals, and are especially relevant at a time when changes to funding for HIV care may affect programs.

Our study demonstrates that, as an alternative to adolescent-specific services, it is feasible to embed youth-friendly HIV services in pediatric and adult services if the particular requirements of the age group are taken into consideration. Many of these requirements, like access to counselors and social workers who assist AYAs to navigate life transitions while facing HIV, can be generalized across diverse settings. Tailoring care to individual contexts could be accomplished through key stakeholder input from AYAs, parents, health care workers, and educators. Our study used focus groups and the community advisory board for this purpose; other suggested methods for settings where such resources are not available include individual interviews and social media platforms.

The AYAs in our study valued confidential nonjudgmental communication. This is a common and consistent finding across various populations, such as adult HIV-positive patients at three health care sites in rural Zimbabwe and AYAs with chronic illnesses in the developed world (Campbell,
Scott, Madanhire, Nyamukapa, & Gregson, 2011; Britto, Tivorsak, & Slap, 2010). Though they are cognizant of their medical needs, AYAs want to be treated respectfully as individuals, not simply the next in a queue of “medical cases.” They derive validation and a sense of being supported from being recognized and listened to. Good quality patient–provider relationships have been found to promote HIV medication adherence in adult patients (Roberts, 2002). In our study, social workers and counselors were often mentioned as being excellent at such communication, and it stands to reason then that the model of youth care should be holistic and multidisciplinary.

Interestingly, the operational suggestions offered by our AYAs would benefit patients of all ages and they were also practical. Clinic efficiency could be accomplished through clinic flow assessments (World Health Organization, 2009). Extended clinic hours to accommodate students would also accommodate employed adults. Dissatisfaction with waiting times was also seen as problematic at other HIV clinics in South Africa, which is the country with the largest number of people on treatment (Wouters, Heunis, van Rensburg, & Meulmans, 2008).

Some ideas were age and disease specific. HIV-positive AYAs on treatment expressed needs specific to learning how to navigate life issues in the context of their disease. Our participants highlighted points that are consistent with the recommendations of the National Adolescent Friendly Clinic Initiative in South Africa, which advocates making services relevant to adolescents available and accessible. These suggestions include incorporating psychosocial care, providing medication without stock-outs, providing information and education, training staff about how to be adolescent-friendly, providing individualized assessments and care, and maintaining continuity of care (World Health Organisation, 2009). Further, maintaining confidentiality, extending clinic hours, and using peer influence to reach difficult-to-engage AYAs have been described as principles for the provision of reproductive health services for HIV-positive AYAs (Johnson et al., 2003). The need for sexual and reproductive health care and education for HIV-positive AYAs was expressed in our study and has been emphasized before in a setting in sub-Saharan Africa (Hodgson, Ross, Haamujompa, & Gitau-Mburu, 2012).

Of concern to the clinic transition process under way, our findings suggest that AYAs perceive clinic transfers negatively. To them, trust and understanding is based on constancy and familiarity, which would be broken in the context of a transfer. In the same way they valued confidentiality about their HIV status when it came to healthcare workers, they also feared inadvertent status disclosure and resulting stigmatization by community members if they were to be seen at community clinics. These fears are not unfounded: one study reported that even when adolescents attended HIV prevention services participating in youth-friendly initiatives in Cape Town, South Africa, they continued to face bad staff attitudes and confidentiality breaches (Mathews
et al., 2009). Stigma is attached to HIV acquisition through high-risk behaviors (Wiener, Korth, Battles, & Pao, 2011), and even though most of our participants were infected perinatally, they felt that this would be disregarded and that the potential for discrimination would remain. There is also a clear concern about service provision at community clinics, noted before in the setting of HIV-positive women accessing antenatal care (Laher et al., 2012), which ranges from bad staff attitudes to drug supply shortages. Implied in these findings is the role for social services to counsel patients about successfully navigating care transitions.

While our study was in the context of transfers necessitated by funding stream changes, in other settings transfers may be necessary for different reasons like decentralization away from specialized units, age-dependent transition from pediatric into adult clinics (Vijayan, Benin, Wagner, Romano & Andiman, 2009), or patient-related factors like travel for school. We recommend a structured transfer process so that AYAs are provided with sufficient time and resources to phase into their receiving clinics. To help ensure continuity of treatment, physicians and nurses should empower AYAs with relevant knowledge and practical scenario planning. For example, a plan addressing how to avoid treatment interruption if the receiving clinic experiences drug stock-outs is relevant for our study group. To allay anxiety and facilitate acceptance, we also recommend that social workers and counselors hand over cases to their peers at the receiving clinic and if possible arrange introductions for AYAs.

Our major limitation was the low proportion of participation. The fourth focus group had been intended for AYA males from the adult clinic but was changed to a mixed-gender group owing to the poor participation in this demographic. Challenges encountered during recruitment included incorrect, out of order, or unanswered telephone numbers, as well as declining participation directly and indirectly by not arriving for the focus group. The authors consider the most likely reason for poor participation to be a fear of implied status disclosure in a peer group setting. Only one participant had disclosed to a friend, which supports this as a reasonable explanation.

The study context, in specific gender and group dynamics, may have influenced participant responses. Because the facilitators and most of the group participants were females, the effect of gender dynamics was probably minimized for female participants. However, it may have contributed to low participation by males in the fourth focus group. Because it was a group setting, AYAs may have been more likely to give socially desirable replies, especially in the context of a mixed-gender group. Additionally, the participants were not familiar with the facilitators, which may have altered their comfort levels and responses. Finally, there were more females in our sample. Male and female participants may experience the HIV clinics in a different manner.
In conclusion, the AYAs interviewed in this study provide multiple insights into how care settings can provide youth-friendly HIV treatment services by integrating social support services to complement medical care. Our findings confirm that HIV treatment services should be youth-friendly and also cater to the specific needs related to growing up with HIV. Because AYAs express significant anxiety about clinic transitions, further research is needed to understand if the AYAs’ negative perceptions of clinic transfer will have negative effects on retention in care and treatment, and the role of social services during care transitions.

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