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Meeting the needs of adolescents living with HIV through Home Based Care: Lessons learned from Tanzania

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# Abstract

**Purpose**Home based care is central to HIV care and support throughout Africa. Most programs have not addressed the unique needs of adolescents living with HIV, who display lower retention in HIV care and treatment adherence. This study examined the experiences of adolescents living with HIV in Tanzania in order to identify ways to improve home based care to better meet their needs.

**Methods**

We conducted a qualitative study in Dar es Salaam and Tanga Region consisting of in-depth interviews with 14 adolescents living with HIV, 10 primary caregivers, and 12 providers assigned to their households. Interviews examined adolescents’ experiences of growing up with HIV, perceptions of current home based care, and challenges in increasing acceptability of services.

**Results**

We found the program did not align well with adolescents’ expectations. Adolescents felt home based care to be more relevant to their caregivers and did not form independent relationships with providers. They expressed anxiety that participation might lead to inadvertent disclosure of their status and consequent discrimination. Both adolescents and their caregivers felt disappointment that no material or financial support was available despite widespread poverty, although they appreciated receiving psychosocial support and practical referrals. Providers demonstrated motivation to work with adolescents but acknowledged lacking requisite skills such as ways to communicate with young people and key messages to deliver.

**Conclusions**

Despite challenges, we identified feasible adaptations to make home based care more adolescent-centered. These include actively engaging adolescents in program design, improving provider training in communication with adolescents, and proactively addressing unrealistic expectations. Finally, increasing referral links to a wider range of services could improve program effectiveness by integrating it into a broader development approach.

# Key Words

Tanzania, Home Based Care, adolescents, caregiver, health services, qualitative research

# Meeting the needs of adolescents living with HIV through Home Based Care: ****Lessons learned from Tanzania****

Joanna Busza, Giulia Besana, Pasiens Mapunda and Elizabeth Oliveras

# ****1.0 Introduction****

Home Based Care (HBC) remains a cornerstone of HIV care and support, particularly in high-prevalence African countries. Having evolved from palliative care, standard HBC now provides a much wider constellation of services, including supporting treatment initiation and adherence, HIV counseling and testing for partners and family members, and long-term psychosocial care ([Evidence for Action Research Programme Consortium, 2010](#_ENREF_7)). HBC is delivered through a range of models, with providers variously referred to as lay health workers, community health volunteers, adherence supporters, expert patients, and peer counselors ([Wringe, Cataldo, Stevenson, & Fakoya, 2010](#_ENREF_23)). HBC providers tend to be well-respected older women from the communities they serve, who work voluntarily or receive a small stipend. In many programs, they are living with HIV themselves and thus able to provide empathy as well as practical guidance ([Chang et al., 2010](#_ENREF_5)). Recent reviews suggest that HBC programs, although diverse, can increase uptake of HIV testing and treatment and improve engagement in care, leading to better physical and mental health outcomes ([Harding et al., 2005](#_ENREF_9); [Kabore et al., 2010](#_ENREF_11); [Scanlon & Vreeman, 2013](#_ENREF_16)).

Most programs have not focused explicitly on adolescents (10-19), however, who comprise a growing population among people living with HIV, with unique needs and experiences. Globally, two million adolescents are estimated to be living with HIV, 85% of whom live in sub-Saharan Africa ([USAID, 2012](#_ENREF_20)). Those who were vertically-infected are coming of age at a time of increasing access to treatment and can expect to live longer, healthier lives than previous cohorts ([Ferrand et al., 2009](#_ENREF_8)).

HBC programs are not always well equipped for younger clients. Research suggests that young people can feel uncomfortable with available HIV support services ([Birungi, Obare, Mugisha, Evelia, & Nyombi, 2009](#_ENREF_2)), and often exhibit lower rates of retention in care and adherence to antiretroviral treatment (ART) ([Bain-Brickley, Butler, Kennedy, & Rutherford, 2011](#_ENREF_1); [Simoni et al., 2007](#_ENREF_17)). As HBC programs adapt from treating opportunistic infections to addressing psychosocial needs and supporting treatment across the life course, they will need to better target young people living with HIV. This paper examines the experiences of a subset of adolescents (aged 15-19) in Tanzania who were vertically infected with HIV and subsequently enrolled in a local HBC program. Among this age group, 1.3% of girls and 0.7% of boys are living with HIV and require targeted support to meet their unique needs as they transition into adulthood ([United Nations Tanzania, 2011](#_ENREF_19)).

Pathfinder International has provided community based HBC for close to 25,000 people living with HIV in Tanzania through the Tutunzane II program (“let‘s take care of one another” in Swahili). Approximately 1,200 HBC providers offer support and assistance in 5 regions and 19 districts of Tanzania. In additional to support and information, the HBC package includes treatment adherence support, referrals to clinical services, nutritional guidance, HIV prevention advice, and, in some locations, home counseling and testing for HIV for household members of clients.

The HBC program did not specifically tailor its services to the needs of youth, and just 5% of its clients were aged 15-24 despite the fact that 20% of adults living with HIV in Tanzania were in this age group ([THMIS, 2008](#_ENREF_18)). The Tutunzane II Program thus decided to assess how adolescents, their caregivers, and HBC providers perceived their roles within HBC care to determine if it was meeting the needs of young clients. This study aimed to highlight the program’s strengths and weaknesses and identify strategies to make it more welcoming and effective for young people.

# 2.0 Methods

We conducted a qualitative study that explored experiences of adolescents living with HIV, their primary caregivers, and HBC providers assigned to their households. The study was conducted in Tanzania’s capital, Dar es Salaam, and Tanga region, to include both urban and rural sites where significant numbers of adolescents were enrolled in HBC. Dar es Salaam has the second highest HIV prevalence in the country (9.3%), with a prevalence of 3.2% among 15-24 year olds. Tanga‘s HIV prevalence is 4.8% for the adult population and 1.8% among 15-24 year olds ([THMIS, 2008](#_ENREF_18)). Disaggregated data are not available for more specific age groups such as all adolescents ( 10-19) or young people (10-24).

Fieldwork took place between January and March 2011. Two male and 2 female fieldworkers, with prior qualitative research experience with marginalized groups were hired as field researchers. We held a preparation workshop with emphasis on building rapport with adolescents, stressing confidentiality and anonymity, and providing opportunities to practice approaching adolescents and using the study tools. Fieldworkers were also trained to provide referrals to local support organizations and social services to address any needs emerging during interviews. Regular debriefing sessions were held throughout the data collection period to provide feedback to fieldworkers regarding their interviewing style and allow problems to be rectified promptly.

*2.1 Recruiting and data collection*

We used purposive sampling to recruit 8-10 HBC providers from each site to participate in focus group discussions (FGD). Providers were selected if they had prior experience working with young people living with HIV. We conducted two FGD to introduce the study in each site and orientate providers to eligibility criteria for recruitment of adolescents into the study, followed by in-depth interviews with those providers who reported the most experience with young clients. We asked them to compare their work with adults to that with adolescents and identify any unique needs they had observed. Findings were used to develop interview guidelines for in-depth interviews conducted with adolescent clients and their caregivers.

The providers assisted in identifying and enrolling eligible adolescents in the study; this avoided causing distress by contacting adolescents directly or inadvertently disclosing their HIV status to others. It also provided the opportunity for young HBC clients to ask questions about the study and discuss any concerns with a familiar person. We interviewed adolescent HBC clients who were aware of their HIV status and consented to participate. Fieldworkers scheduled interviews in consultation with HBC providers to ensure respondents felt comfortable being approached by the study team and interviews took place at a convenient time. Following the interview, they were asked if they lived with a primary caregiver and if so, whether that person could be approached for an interview.

Topic guides for all interviews addressed issues that emerged in provider FGDs and asked respondents about their experiences of living with HIV (or caring for someone who did) and perceptions of the HBC program, including open-ended questions about enrolment, timing and frequency of contact with HBC providers, likes and dislikes within the program. More specific questions probed about the quality of adolescents’ relationship with providers focusing on ease of communication , levels of trust, and reliance on HBC for information, counseling, and psychosocial support . Adolescents’ sexual and reproductive health needs and to what extent these could be met through the HBC program were also examined and analyzed separately; results have been published elsewhere ([Busza, Besana, Mapunda, & Oliveras, 2013](#_ENREF_3)).

Interviews were conducted in Swahili and transcribed by the fieldworkers themselves. An experienced translator was hired to translate the interviews into English. We monitored quality of the interview transcripts by back-translating randomly selected excerpts from interviews as well as checking the original audio recordings.

*2.2 Analysis*

Names of individuals, family members, or villages were removed from transcripts prior to analysis. For the purpose of this paper we restricted analysis to HBC clients aged 15-19 in order to focus on the specific HIV care and support needs of adolescent clients; we were unable to recruit younger respondents due to restrictions set by the National Institute for Medical Research guideline for health-related research.

After data familiarization, we (first two authors) developed a coding framework using themes identified both *a priori* (based on the aims of the study e.g. attitudes toward HBC, descriptions of services received, understanding of psychosocial support and self- identified care needs ) as well those emerging directly from the findings (e.g. fear of disclosure, expectations for material support). Using the qualitative data analysis software program, NVIVO, coding was done simultaneously and cross-checked across the framework. We then compared codes within and across respondent categories. While we did find some differences in emphasis between adolescents’, caregivers’ and providers’ concerns and priorities, we did not identify clear thematic variation by gender or by rural or urban study site for any of the three types of respondents. Given the relatively small sample size and subjective nature of responses elicited through open-ended questions, however, this could be a result of the study design rather than a true reflection of homogeneity.

*2.3 Ethics*

Ethical approval was obtained from the London School of Hygiene and Tropical Medicine and the Tanzanian National Institute of Medical Research. Fieldworkers obtained written informed consent from all participants, and permission was sought for recording interviews. Consent from a parent or legal guardian was required for participants younger than 18, in keeping with Tanzanian national research guidelines on studies involving children. All participants received assurance that refusal to participate in the study would not affect their relationship to Tutuzane II services.

# 3.0 Results

Following the FGD with HBC providers, we interviewed 14 adolescents, and 10 caregivers as well as 12 HBC providers with extensive experience working 15-19 year old clients. All interviewed adolescents had lived with HIV since infancy and grappled with issues related to school, friendships, and sexual development while living with a chronic illness requiring lifelong treatment. All were presumed to have been vertically infected, although this could not always be verified. Among adolescents, there were 5 girls and 9 boys. Twelve reported being on HIV treatment, while two were not yet eligible. Nine out of ten caregivers were women, comprising mothers, grandmothers or aunts; one caregiver was a father. Similarly, only two of the 12 HBC providers were male. Interviews with all types of respondents were split almost evenly between study sites.

*3.1 Adolescents’ participation in care*

Unlike adults who independently took up HBC, adolescents had been enrolled as young children, often alongside a parent prior to having been told of their own status. Their relationships with HBC providers appeared passive, while parents or guardians had greater direct contact. Indeed, it proved difficult to elicit information on HBC from adolescents; although they could identify their provider, they generally viewed HBC providers as a resource for their caregivers:

She talks with uncle. So there are some items that I don‘t understand. However, uncle knows. They talk. My uncle communicates with her, really, .... I am normally not around. ... She sometimes comes to greet us. Or she comes with their certain topics to talk about. (Male, 15, Dar es Salaam)

I cannot remember when she started. However, I used to see her coming to serve mother. ...Only mother. ... I have never seen her serving me even once. ... She used to call mother and she would sit there with her. That’s all. ... I was allowed [to join] but I normally used to take leave of them. ...I have not noticed what they used to talk about. (Male, 15, Tanga)

Respondents did not consider themselves to be personally engaged with HBC, associating visits with health promotion on medication, basic hygiene, and opportunistic infections.

**Interviewer**: Can you tell me what kind of services does she provide you?

**Respondent**: Generally she informs me on the usage of my medicine. I should not stop. How I should live. And that I have to eat well.

**Interviewer**: What else does she tell you?

**Respondent**: No more; only that. (Female, 18, Tanga)

**Interviewer:** What significant topics do you discuss with them when they come around?

**Respondent:** Topics like how to live with other people; what HIV/AIDS is all about. ...They just educate/inform you. ...They counsel you on life – that is all. ...

**Interviewer:** Do the HBC providers visit you frequently.

**Respondent:** No, not really. ... Once in a month.

**Interviewer:** What do you do when she comes around?

**Respondent:** She just comes around to monitor your progress. (Male, 18, Tanga)

When fieldworkers probed further, to assess whether adolescents felt they could confide in providers and share their emotions or fears, adolescents voiced concerns about confidentiality, worrying that HBC providers might inadvertently disclose their status:

I would like the providers to keep the secrets of their clients. …These service providers have a tendency of broadcasting their clients‘ problems [HIV/AIDS] that I don‘t like at all. They tell and tell. I don‘t like it. There should be some confidentiality. (Female, 15, Dar es Salaam)

Caregivers and HBC providers confirmed that anxiety over disclosure dissuaded adolescents from participation in HBC. They attributed this to general adolescent insecurities:

***Respondent****: they [adolescents] come across several stumbling blocks – for instance when a youth knows that you are an HBC provider, he runs away from you. Others hide themselves while others just refuse getting associated to the provider. Just rejects him/her.*

***Interviewer****: Is this problem particular to the youth or to all the patients?*

***Respondent****: The problem is more apparent to the youth. ... [It is] their age. There is a generation gap. The youth would not like transparency, unlike older people. This thing can hardly be avoided.*

*(Mother of female, 15, Dar es Salaam)*

No actual breaches of privacy were reported, however, and providers made clear that they recognized the importance of discretion:

*...[The] person wants to make it a ‘secret’ between the two of you only. Most of these youth are popular among themselves, and since everyone knows what I do, the ‘secret’ will easily ‘leak’ if we (the client and I) are seen meeting frequently. They wouldn’t like that. (Female provider, Tanga)*

Providers often made special arrangements to avoid attracting unwanted attention, such as visiting households when certain members were absent, meeting clients in a neutral location, or disguising their intentions (e.g. pretending to be visiting from a church).

***Respondent****: ... when she comes there, she leaves a message with my mother, as I’m most of the time out of home; and they just talk as normal conversations so as to “blind” other people.****Interviewer****: So do you like that?****Respondent****: Yeah, I like it because other people are not aware of what is going on, when she comes, they just talk as normal. Other people know that she is a home based care provider, but they do not know [that] when she comes it is for me. They do not know. (Female, 18, Tanga)*

*3.2 Perceptions of Current Services*

Adolescents were confused about the intended role of HBC. Some were disappointed that providers were unable to help financially:

***Interviewer****: What kind of services do you want to get?*

***Respondent****: They should bring money as their contribution.*

***Interviewer****: What about your health, what would you want them to do?*

***Respondent****: Food. ... That’s it. ...*

***Interviewer****: Tell me, is there anything you would wish this woman, a care provider to give you? ...What would you want her to do?*

***Respondent****: She should come to provide assistance. ... juice and money ... That is all! (Male, 15, Dar es Salaam)*

Observations that providers came “empty handed” may have been learned from parents, who also complained about lack of financial assistance. There appeared to be misconceptions and unrealistic expectations for HBC:

I wish she could be in charge of getting the medicine, even if it is money, okay. If we are sure of that, ... [that] she comes and puts [her] hand in her pocket to give us something. ... The provider has come to visit me, but not empty handed (Mother of female, 19, Tanga)

**Respondent**: ... the stumbling blocks in my path are clothing, shoes and what to put in my tummy – that is all. ... As far as this lady [HBC provider] is concerned, to say the truth, I have not seen her with something in her hand as a way of assistance. … You see, even if it is something very little/small – it should get to the patient concerned.

**Interviewer**: What, for instance? What would you like them to bring? …

**Respondent**: Cooking oil, flour, beans, soap… (Father of male, 15, Dar es Salaam)

Yet adolescents also suggested that HBC providers offered hope and confidence, which they valued, as well as providing special attention:

... you are given some hope and you relax even if you had some kind of tension (Male, 18, Tanga)

Adolescents also appreciated practical assistance from HBC providers including referrals to other organizations or help in arranging medical appointments:

One day she visited us and found me at home. She asked my mother why I was not at school. Mother said that she had problems. She helped mother get a certain letter from our local Government, which helped me attend an interview for Form I. I thank God that I passed the interview and I started going to school again. …She [HBC provider] helped me in that she showed us the way. … we didn‘t know where to go and what to do. I would not have gone to school until now. (Female, 15, Dar es Salaam)

Say if you get ill, and possibly that your date for clinic is yet to arrive, they refer [you to the] youth hospital for further management. … All you do is to telephone her and arrange. .... You explain your problem and she serves you fast; and off you go. (Male, 18, Tanga)

Others gave examples of where HBC providers used their own resources to procure food, medicines, or treats. Although welcomed, providing small gifts required providers to exceed their HBC remit:

**Respondent** First of all, if I don’t have school items such as exercise books, she buys for me. And when I’m hungry she buys me chips I eat, and many other things.

**Interviewer:** What about the side of your health and how you fall sick? What kind of services does she provide?

**Respondent:** She brings me fast acting pain killers where I get relief after 5 hours. ... All her services please me. (Female, 14, Dar es Salaam)

Sometimes she visits me after three days or so. At other times she may visit me once in a week. ...She gives us whatever she has in her hands.For example she gives out soap, Dettol, toilet soap and even her own money if she has it. (Male, 19, Tanga)

While providers were eager to help, purchasing supplies or food for clients could cause both economic and emotional strain, and risked the sustainability of the program in the longer term.

*3.3 HBC Providers’ Experiences*

HBC providers enjoyed serving adolescents, considering them a priority, as summarized by a provider from Tanga: “I feel good to help any person. To help a youth - I like it even more.” Interacting with young people was seen to require a different approach than working with adults, including building rapport and providing information in a tactful way:

It is different in that adults get to understand you more easily and quickly whereas it might take two, three or more sessions to get a youth to understand you. (Female provider, Tanga)

... we go according to youth and their preferences. For example on the side of language, we use like ‘how is it?’ for greeting. Words like ‘you get me?’ ‘peace?’ (Male provider, Tanga)

While acknowledging that adolescents needed additional support, providers did not always feel well-equipped for this role:

You see, talking to an adult is different from talking to a young person. So if I could get training geared more towards children/young people it would help a great deal. I am only using experience and I am not really sure about what I am doing and I don‘t even know where I might be going wrong. (Female provider, Dar es Salaam)

**Interviewer**: Do you think that you personally have been well prepared/ trained to serve these clients who are young people?

**Respondent**: Not yet. We were not trained to specifically deal with the youth. Our preparation was general to serve all groups of people. (Female provider, Tanga)

Several providers discussed how working with HIV-positive adolescents affected their own emotional health. “Feeling bad” and sadness were reactions to encountering children growing up with HIV. Providers observed the lack of opportunities available to youth living with HIV:

The youth who still go to school need mostly food; the economic status of families is, to say the least, very poor so you can imagine one is HIV-positive and at the same time one lacks sufficient food. The second big need for those who are still in school is to study, but then again there is a problem of funds for the schooling. ..if they lack anything they come rushing to me asking for help. And I have just a meager income. If there would be a way to provide them with food at schools or somehow be aided in getting some food it would help a lot. (Female provider, Dar es Salaam)

I thank the Lord that the youth I meet are at least from well- to-do- families. But others are so poor that they need assistance. ... Therefore when you meet a youth from a poor family, s/he may say; ‘Brother, I have nothing. If you are in a position, give out 500 shillings for a cup of milk’. (Male provider, Tanga)

Thus although providers recognized that unrealistic expectations had developed, they did not feel able to deflect these. They agreed that providing information and counseling without material aid was a shortcoming of the program:

We have nothing and so we go to clients with empty-hands. You just give him/her (the patient) mere words, no any material. Truly, you feel indebted. Therefore, if we had had some small items, it would really help to entertain hence motivate others to join the group. (Female provider, Dar es Salaam)

# 4.0 Discussion

The HBC program delivered a wide range of services with which many clients expressed satisfaction. For the most part, however, we found a similar “disconnect” to those found in other studies, in which program aims did not align well with adolescent’s expectations or needs ([Birungi et al., 2009](#_ENREF_2); [Li et al., 2010](#_ENREF_12)). A particularly salient finding was that adolescents feared participation in HBC would reveal their HIV status. Other studies have also observed perceived or anticipated stigma posing barriers to program enrolment and retention ([Dlamini et al., 2009](#_ENREF_6); [Merten et al., 2010](#_ENREF_13)). The program might benefit from eliciting adolescents’ ideas on acceptable ways for HBC providers to engage with them without exacerbating these anxieties. It was encouraging, however, to see providers acknowledge adolescents’ fears and take precautions to maintain secrecy. This could be built on, with providers’ taking a more proactive role in helping children with HIV transition into adolescents, including encouraging and facilitating disclosure to others ([Pinzon-Iregui, Beck-Sague, & Malow, 2012](#_ENREF_15); [Vaz, Eng, Maman, Tshikandu, & Behets, 2010](#_ENREF_21)).

Currently, however, adolescents viewed HBC providers as health promoters rather than counselors or confidantes, limiting psychosocial support. This was partly because adolescents did not perceive themselves to have an independent relationship with providers, but was also related to providers’ inadequate skills for working with adolescents. A more adolescent-centered approach could encourage providers to clearly delineate service delivery to adolescents from that for parents and caregivers, and provide these on adolescents’ own terms. Recruitment of younger HBC providers or adoption of a peer support approach might also help overcome communication barriers ([Naar-King, Outlaw, Green-Jones, Wright, & Parsons, 2009](#_ENREF_14)).

While acknowledging these challenges, HBC providers felt motivated to work with adolescents, whom they considered especially vulnerable. As has been found in other contexts, they felt frustration at being unable to address wider structural factors such as poverty, insufficient education and livelihood opportunities ([Celletti et al., 2010](#_ENREF_4); [Hermann et al., 2009](#_ENREF_10)). Caregivers and adolescents also complained of being unable to afford school fees, books, supplies, and adequate food ([Weiser et al., 2010](#_ENREF_22)). In response, providers sometimes offer their own resources. Clients and other household members focused heavily on whether providers could offer material assistance or address their physical needs, whereas psychosocial services such as counseling, support, and outreach were considered to be secondary benefits. HBC programs need to address these expectations more explicitly, not only to deflect unrealistic demands on the program’s or providers’ own resources but also to highlight the integral role mental health and psychosocial well-being can play in young people’s physical and emotional development . Direct communication with families about what the program can realistically provide might help address expectations, as might situating HBC programs within a broader set of development initiatives, such as income generation, microfinance, nutritional support, and educational opportunities. Clearer explanation of the purpose of one-to-one and family-centered counseling as well as consultation with adolescents’ regarding their own priority concerns and questions might also increase the acceptability and relevance of the psychosocial component of HBC.

Our study has several important limitations. First, we recruited adolescents suggested by HBC providers, who may have been purposively selected and likely to give more positive feedback than other clients. It is also possible that they felt uncomfortable sharing personal information if they knew their caregivers were going to be interviewed. Nonetheless, respondents did express reservations about the HBC program, and we asked adolescents to nominate a caregiver *after* their interview, emphasizing it was entirely voluntary to do so. The experiences and issues raised are similar to those in other studies of young people living with HIV, suggesting we captured a realistic portrayal of challenges that adolescents faced in receiving home based care. Second, we were not able to recruit younger adolescents, namely those 10-14, who are likely to have different experiences and needs and may require specific adaptations within an HBC program targeted for young people. Finally, although our study sample was adequate for the purposes of an assessment of Pathfinder’s HBC program in two of its key locations, the number of respondents precluded meaningful analysis by gender or urban/rural residence.

# 5.0 Conclusions

As suggested by the HBC program’s struggle to enroll adolescents living with HIV, providers were not adequately meeting the needs of adolescents. Yet HBC providers demonstrated eagerness to overcome identified challenges and requested support and additional preparation. Our results suggest several feasible adaptations to program delivery. First, adolescents living with HIV could be more proactively engaged with HBC program design, to ensure their views inform service delivery and to mitigate their fears that participation in the program could lead to inadvertent disclosure of their status and consequent stigma. Second, professional development for providers should focus on building skills in communication with adolescents, including how to balance relationships with children and caregivers in the same household. Finally, given the backdrop of poverty and HBC clients’ needs beyond health, the HBC program would benefit from increasing links to a wider constellation of referral services. It is also important to continue to assess the needs of all stakeholder groups as HBC evolves to become more attentive to adolescents’ needs to ensure program effectiveness and sustainability.

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