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Published in:
African Journal of AIDS Research

DOI:
10.2989/16085906.2012.734987

Publication date:
2012

Document version
Publisher's PDF, also known as Version of record

Citation for published version (APA):
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To cite this article: Vivian Midtbø, Violeth Shirima, Morten Skovdal & Marguerite Daniel (2012): How disclosure and antiretroviral therapy help HIV-infected adolescents in sub-Saharan Africa cope with stigma, African Journal of AIDS Research, 11:3, 261-271

To link to this article: http://dx.doi.org/10.2989/16085906.2012.734987

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How disclosure and antiretroviral therapy help HIV-infected adolescents in sub-Saharan Africa cope with stigma

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HIV-related stigma has a major impact on the health and psychosocial wellbeing of HIV-infected children and youths. While there is some debate about the extent to which improved access to antiretroviral therapy (ART) contributes to a reduction in HIV stigma, we know little about how adolescents who know their HIV status and who are enrolled in ART experience and cope with stigma. The aim of the research was to understand and identify the pathways between HIV-status disclosure, ART, and children’s psychosocial wellbeing, including from the perspective of adolescents themselves. Two qualitative studies were carried out, in Botswana and Tanzania, in 2011: 16 adolescents and three healthcare workers were enrolled in Botswana, and 12 adolescents and two healthcare workers were enrolled in Tanzania. The data were collected through individual and group interviews as well as participant observation. The recorded interviews were transcribed and analysed using thematic network analysis. The findings indicate that HIV-status disclosure enabled adolescents to engage effectively with their ART treatment and support groups, which in turn provided them with a sense of confidence and control over their lives. Although the adolescents in the two studies were still experiencing stigma from peers and community members, most did not internalise these experiences in a negative way, but retained hope for the future and felt pity for those untested and uninformed of their own HIV status. We conclude that disclosure and good HIV-related services provide an important platform for HIV-infected adolescents to resist and cope with HIV stigma.

Keywords: Botswana, HIV/AIDS, medication adherence, qualitative research, social support, Tanzania, thematic network analysis, treatment support, youths

Introduction

The situation of people living with HIV has changed dramatically following the rollout of antiretroviral therapy (ART). ART has shifted HIV infection from being a terminal disease to a chronic illness. The improved availability of ART and associated services has helped suppress the replication of the virus in many HIV-infected people, enabling them to return to socially and financially productive lives. There is some debate about how this normalisation of HIV infection and AIDS illness may impact HIV stigma. Commentators from Botswana (Wolfe, Weiser, Leiter, Steward, Percy-De Korte, Phaladze et al., 2008), Kenya (Kaai, Sarna, Luchters, Geibel, Munyaio, Mandaliya et al., 2007), Haiti (Castro & Farmer, 2005) and Mozambique (Pearson, Micek, Pfeiffer, Montoya, Matediane, Jonasse et al., 2009) have argued that improved access to ART is associated with reduced levels of HIV stigma. A Tanzanian study found that ART contributed to a degree of normalisation of HIV infection, yet it continues to be stigmatised as a ‘moral disease,’ which undermines disclosure and voluntary counselling and testing (Roura, Urassa, Busza, Mbata, Wringe & Zaba, 2009; Roura, Wringe, Busza, Mbata & Zaba, 2009).

Reconciling this debate, a recent study by Campbell, Skovdal, Madanhire, Gregson & Nyamukapa (2011) found that the improved availability of ART in Zimbabwe did not necessarily reduce the presence of stigma, but provided people living with HIV (PLHIV) — through their ability to take control of their own health and return to living socially and economically productive lives — with the opportunity to resist and challenge stigmatising attitudes. They did so by constructing an empowering distinction between ‘us’ (the self-identified PLHIV who live positive and productive lives) and ‘them’ (the stigmatising, ignorant and untested others). As we are unaware of any previous study discussing the interface between ART access for adolescents and their ability to cope with stigma, we sought to build on that finding in relation to adolescents in Tanzania and Botswana, and to explore how HIV-infected adolescents on ART manage to cope with HIV stigma.

HIV stigma and adolescent health and wellbeing

Several studies have highlighted how fear, ignorance and a lack of basic knowledge about HIV and AIDS contribute to the stigmatisation of PLHIV (e.g. Campbell, Foulis, Maimane & Sibiya, 2005; Holzemer & Uys, 2005; Mutalemwa, Kisoka, Nyigo, Barongo, Malecela & Kisinja, 2008; Nyblade, MacQuarrie, Kwaresigabo, Jain, Kajula, Philip et al., 2008; Akande, 2010). Children and adolescents living with HIV, as well as children living with family members with HIV, are likewise subjected to gossip, discrimination and hostility because of their association with HIV (Goffman,
The mental health of children and youths with HIV infection

Living with HIV and the pressure to comply with a treatment regimen is undoubtedly stressful. A number of studies have highlighted the psychological distress experienced by HIV-infected children and youths. Research in North America suggests that adolescents living with perinatally acquired HIV have higher rates of psychiatric illness than their uninfected peers (Koenig, Nesheim & Abramowitz, 2011; Malee, Tassiopoulos, Huo, Siberry, Williams, Hazra et al., 2011). This can further impact disease progression, as studies of HIV-positive adults in the United States found evidence that stress and traumatic life events are associated with non-adherence to antiretroviral medication (Mugavero, Ostermann, Whetten, Leserman, Swartz, Stangl & Thielman, 2006; Leserman, Ironson, O’Cleirigh, Fordiani & Balbin, 2008). A literature review examining the role of depression, stress, and trauma in HIV-disease progression reports that psychosocial factors negatively affect disease progression. Whether it is depression that puts a person at greater risk of disease progression, or rather disease progression that causes increased risk of depression, is still under debate (Leserman, 2008). Interestingly, however, recent evidence suggests that children and adolescents who live with someone who is HIV-positive and who are not infected with HIV themselves, have greater mental health problems than their HIV-infected peers (Malee et al., 2011). Malee et al. (2011) proposed that this difference may be explained by the immediate enrolment of HIV-infected children and youths into treatment support networks — an opportunity for support generally unavailable to HIV-affected children and youths.

Only a few studies have examined the mental health challenges of children and youths living with HIV in sub-Saharan Africa (e.g. Menon, Glazebrook, Campain & Ngoma, 2007; Li, Jaspan, O’Brien, Rabie, Cotton & Nattrass, 2010; Petersen, Bhana, Myeza, Alicea, John, Holst et al., 2010). A study by Petersen et al. (2010) found that over half of their South African study participants showed signs of internalised stigma, and they argue that stigma can also lead to the inability of HIV-infected children to express their distress. The study also found that factors associated with coping with distress included the availability of life-prolonging medications, strong family social support, and extensive supportive networks (Petersen et al., 2010).

The importance of disclosure to children and youths with HIV infection

Despite the fact that non-disclosure of HIV status to HIV-infected children is a common barrier to their ART adherence (Nabukeera-Barungi, Kalyesubula, Kekiitwana, Byakika-Tusiime & Musoke, 2007; Polisset, Ametonou, Arrive, Aho & Perez, 2009), several studies have reported low levels of disclosure to children about their own HIV-positive status (Biadgilign, Deribew, Amberbir, Escudero & Deribe, 2011; Kallem, Renner, Ghebremichael & Paintsil, 2011; Vaz, Maman, Eng, Barbarin, Tshikandu & Behets, 2011). Parents or caregivers may choose not to disclose a child’s own HIV-positive status to the child for a number of reasons. These include fear of discrimination towards the family if the child reveals their status to others, fear of being judged by the child, as well as the perception that young children are unable to understand the implications of being HIV-positive and taking ART (Vaz, Corneli, Dulyx, Rennie, Omba, Kitetele & Behets, 2008; Vreeman, Nyandiko, Ayaya, Walumbe, Marrero & Inui, 2010). A study by Vaz et al. (2011) found that some caregivers provide children with deflecting information about the child’s health, such as including some information about the disease but avoidance of naming the disease. Vreeman et al. (2010) report on a Kenyan study that explored the perceived positive impacts of disclosing HIV status to children. They found that despite caregivers’ fears of telling a child about his or her own HIV-positive status, they nonetheless perceived positive impacts from disclosure, including the child’s improved ART adherence and access to supportive networks. Observations made in Uganda (Bikaako-Kajura et al., 2006) and Zambia (Menon et al., 2007) where children knew about their HIV infection and were enrolled in an ART programme found that disclosure was related to good adherence, and the children had fewer emotional problems compared to those who had not been disclosed to.

Only a few studies have sought children’s and adolescents’ perspectives on the perceived impact of their HIV-status disclosure. Through their work with HIV-positive youths in the Democratic Republic of Congo, Vaz et al. (2008) and Vaz, Eng, Maman, Tsikandu & Behets (2010) concluded that a large majority of children and youths prefer to know their HIV status, despite the fact they may feel sad and afraid immediately after the disclosure. Furthermore, a study in Brazil (Abadía-Barrero & Castro, 2006) shows how non-disclosure can create confusion and mistrust in children, compromising knowledge of the disease and leading to increased HIV-risk behaviour.

This brief review of previous research highlights the importance of understanding and identifying the pathways between HIV-status disclosure, ART and children’s psychosocial wellbeing, not least from the perspective of adolescents themselves. Against this background, and in our
interest to highlight the ‘agency’ capabilities of African youths, we report on studies that bring forward the perspectives of adolescents, and we explore how, in the context of ART and disclosure, HIV-positive adolescents in Botswana and Tanzania find opportunities for managing their lives and coping with HIV stigma.

**Methods**

The article draws on the findings of two qualitative studies, conducted between June and September 2011, in Tanzania and Botswana. Both were guided by a phenomenological study design which sought to explore the lived experiences of HIV-infected adolescents. Initially the separate studies had slightly different objectives, with the study in Botswana focusing on what contributes to HIV-positive adolescents' capacity to thrive, and the study in Tanzania focusing on how HIV-positive adolescents thrive despite the stigma they face. But in the process of analysing the data, we noticed many similar findings, despite being research conducted in two different countries; consequently, we identified the similar themes and reanalysed the data.

Both studies received approval from the Norwegian Social Sciences Data Services. In addition, the Tanzanian study received approval from the National Institute of Medical Research (NIMR) of Tanzania, while clearance for the Botswana study was granted by the Ministry of Health in Botswana and the Regional Committee for Medical and Health Research in Norway. Rigid ethical guidelines were followed to ensure the participants’ confidentiality and anonymity. The participants were informed that participation was voluntary and that they could withdraw or refuse to answer any question without consequences. Written and informed consent was obtained from the participants, and written or oral consent was obtained from the caregivers of participants under the age of 18 years.

**Study locations and participants**

Botswana is a landlocked country with approximately two million people (CIA, 2011). Botswana has the second-highest level of HIV prevalence in the world (24.8%) for the age group 15–49 years, and it has approximately 16 000 children aged 0–14 with HIV infection (UNAIDS, 2010). Botswana introduced an ART programme in 2002, aiming to offer treatment to all HIV-positive citizens who needed it (AVERT, 2011); by 2009, ART coverage exceeded 90% of those eligible (UNAIDS, 2010). Tanzania is a more populous country, with an estimated 42.7 million people. HIV prevalence in Tanzania is estimated at 5.6%, which includes between 83 000 and 240 000 HIV-infected children aged 0–14 (UNAIDS, 2010). Tanzania initiated an ART programme in 2004, and has since reached an estimated coverage of 32% of adults and 17% of children eligible for treatment (UNAIDS, 2010). The study in Tanzania was carried out within an organisation called ‘Pastoral Activities and Services for people with AIDS Dar es Salaam Archdiocese’ (PASADA), which offers medical and psychosocial support for people living with HIV or AIDS, including children and adolescents. The study in Botswana was conducted at two different sites: a hospice in an urban setting and a hospital in a rural setting. As we found few differences in the findings from the rural and urban settings, the data from the two areas were analysed together.

All the participants were purposefully recruited with help from staff who worked at the sites. Adolescents on ART and whom the NGO or healthcare staff deemed to be articulate and communicative were invited to participate in the study. All the participating adolescents had their HIV status previously disclosed to them. The study in Tanzania included 12 HIV-positive adolescents (7 girls and 5 boys) between the ages of 12 and 14, and interviews with two healthcare staff members. In Botswana, 16 adolescents (10 girls and 6 boys) between the ages of 12 and 20 were enrolled in the study, and three healthcare staff members were interviewed to explore their perspectives on adolescents coping with ART treatment and HIV stigma. The names used here are pseudonyms.

**Data collection and analysis**

In both countries the data were obtained through individual interviews with the adolescents. The Botswana study included two focus group discussions in addition to the individual interviews. Semi-structured interview guides were used for all the interviews. The interview guide used in Botswana covered the positive resources in the adolescents' lives, their relationships with family and friends, their experiences and thoughts about disclosure, and how they handled stigmatisation. In Tanzania the interview guide covered forms and effects of stigma, and coping mechanisms related to stigma. In order to gain additional information about the adolescents’ environment, to observe how they interacted with each other and as part of the selection procedure for the individual interviews we also drew on participant observation. We participated actively in group activities and seminars organised by the healthcare facilities in Botswana and PASADA in Tanzania. Participation enabled us to form an understanding of adolescents’ environment and their relationships to each other; in Tanzania it also helped the researcher to select participants for the individual interviews.

All interviews were recorded. As the study in Botswana was conducted by a non- Setswana speaker, translators were used to facilitate the individual and group interviews with the exception of one interview where the girl being interviewed felt confident enough to carry out the interview in English. The translators used were healthcare staff working at the healthcare facilities. Interviews were transcribed and translated from Setswana into English. The Setswana parts of the interviews were transcribed by a local student. The Setswana transcriptions were then translated back into English by a second local student, without the opportunity to see the transcription of the English parts of the interviews, to make sure his translation would not be coloured by this. The interviews in Tanzania were conducted by the researcher in Swahili, and translated into English by the researcher herself.

The data were analysed using thematic network analysis based on Attride-Stirling’s (2001) four analytic steps: 1) coding the material; 2) identifying themes; 3) constructing the networks, and 4) describing and exploring the thematic networks. Data from the studies in Tanzania and Botswana...
were initially analysed separately and analysis began through basic coding of the transcripts. Data from both studies were then reanalysed within the framework of this article’s aims and objectives. Thirty basic themes emerged, which, through an iterative process involving all the authors of this article, were clustered into 12 organising and more interpretative themes, which in turn were grouped together to make the four global themes that guide the structure of our findings section. On the basis of this analytical exercise, Table 1 was developed by adding a ‘B’ (for Botswana) and/or a ‘T’ (for Tanzania) in brackets after each basic theme, to indicate from which locality the basic themes had emerged.

Findings

Stigma impacts on the lived experiences of HIV-infected adolescents who are enrolled in ART programmes in Botswana and Tanzania. Most of the adolescents reported experiencing various forms of HIV stigma, such as verbal abuse (for example, being called degrading names), being labelled (for example, being given a red ribbon to wear as a sign of disease), and being pointed at. The adolescents also felt that people gossiped about their HIV status, and they sometimes felt discriminated against or rejected by friends and family members. This is exemplified by 14-year-old Lina from Tanzania:

‘My stepmother disclosed my status to everybody; she even told her relatives that I am HIV-positive. It reached a time when I was isolated on a sleeping mat; I was sleeping on the floor while the children of my stepmother were sleeping on the bed…. Other times I was served food on a plate that we used for feeding the chickens and sometimes on a plate with a hole, while her children were served on the good plates.’

In addition to having to deal with stigma, some adolescents reported worrying about getting enough food; time in school lost due to opportunistic infections; and some had also experienced the loss of close family members to AIDS. Despite these challenges and the stigmatising attitudes of

<table>
<thead>
<tr>
<th>Basic themes</th>
<th>Organising themes</th>
<th>Global themes</th>
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<tbody>
<tr>
<td>Initiates antiretroviral therapy (ART) (B, T)</td>
<td>The availability of medication</td>
<td>1. Improved HIV services</td>
</tr>
<tr>
<td>Uses/desires counselling services (B)</td>
<td>Treatment support services</td>
<td></td>
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<tr>
<td>Has hospital check-ups (B)</td>
<td>To be informed about their HIV status helps adolescents understand their life situation</td>
<td></td>
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<tr>
<td>Joins ‘Teen Club’/support group (B, T)</td>
<td>When disclosed to, adolescents are able to take control over their life</td>
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<tr>
<td>Life finally makes sense (B)</td>
<td>Adolescents are strategic about whom they declare their HIV status to</td>
<td></td>
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<tr>
<td>Knows the purpose of hospital visits (B)</td>
<td>Adolescents thrive as a result of their friendships</td>
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<td>Adolescent wants to know his/hers own HIV status (B, T)</td>
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<td>Knows the importance of ART and how to adhere to the medication (B, T)</td>
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<tr>
<td>Knows how to live healthily and positively (B)</td>
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<tr>
<td>Does not disclose to any friend (B, T)</td>
<td>Adolescents seek help</td>
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<td>Does not disclose to anyone outside the family (B, T)</td>
<td>Adolescents ‘fight back’ against stigma</td>
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<td>Only discloses to trustworthy people (B, T)</td>
<td>Adolescents ignore those who stigmatize him/her (B, T)</td>
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<tr>
<td>Advised by caregiver to not disclose (T)</td>
<td>Has family support</td>
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<td>Has friends from the support group (B, T)</td>
<td>Seeks religion</td>
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<td>Able to share problems with others (B, T)</td>
<td>Is able to plan for the future (B, T)</td>
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<tr>
<td>Adolescent gains knowledge and learns from other adolescents (T)</td>
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<tr>
<td>Engages in sports and other leisure activities with friends (B, T)</td>
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<tr>
<td>Adolescent has good friends in school (B, T)</td>
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<td>Adolescent visits social workers (B, T)</td>
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<td>Adolescent reports stigma to adults (B, T)</td>
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<tr>
<td>Adolescent confronts the stigmatizers (B)</td>
<td></td>
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<tr>
<td>Adolescent stigmatises the stigmatizers (B)</td>
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<td>Adolescent ignores those who stigmatize him/her (B, T)</td>
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<tr>
<td>Adolescent is supported by their immediate family (B, T)</td>
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<tr>
<td>Adolescent is supported by their extended family (B, T)</td>
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<tr>
<td>Some adolescents turn to God (T)</td>
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<tr>
<td>Believes it is a strength to know one’s HIV status (B, T)</td>
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<tr>
<td>Adolescent knows he/she is not to blame for the HIV infection (B)</td>
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<tr>
<td>Continues schooling and education (B, T)</td>
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<td>Is able to plan for the future (B, T)</td>
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people around them, four pathways for coping with stigma, emerged from our analyses. These four pathways relate to:

- improved HIV-related services;
- to be disclosed to, and to disclose HIV status to others;
- adolescents’ engagement with their social environment; and,
- adolescents’ individual sense-making (see Table 1).

**Improved HIV services**

In both Botswana and Tanzania ART services are provided free to all citizens eligible for treatment. Availability of medications contributed to a feeling of safety for many of the adolescents interviewed in both Botswana and Tanzania. ART was reported as very important in their lives and was related to being able to live a long life. Adolescents interviewed in Tanzania explicitly mentioned how their CD4 cell counts had been low before initiating ART, and how their health situation had improved after being enrolled in an ART programme.

‘The ART has helped me as I take them as I was directed by doctors. My CD4 [count] was down before starting taking the ART; I am happy my health is improving and my CD4 count is up’ (Pili, age 14, Tanzania).

A boy from Tanzania told a similar story:

‘I was very ill to the point where I couldn’t walk; my aunt used to carry me to the hospital. Since I started the ART, my health has improved. I thank God I am alive and I can do other things on my own, like going to school and coming to the hospital’ (Hamis, age 12, Tanzania).

In both Botswana and Tanzania available treatment and support services that were mentioned included counseling services, hospital check-ups and support groups. Counselling services were talked about as a place where the adolescents could ask questions regarding their health, HIV and general life issues. Most adolescents saw it as very important not to miss their scheduled hospital check-ups. However, one of the healthcare staff in Botswana reported that a common worry among the adolescents was that the hospital check-ups interfered with their school days. This resulted in having to explain to their friends why they had to miss school on these days, without disclosing their status.

The support groups seemed to be an important resource for the adolescents in both Botswana and Tanzania. In Botswana the adolescents had access to ‘Teen Club,’ a peer support group for HIV-positive teenagers. Teen Club can be found in several places in Botswana. The programme combines knowledge and information on various themes (with health personnel available to answer questions) and sports and games activities. In Tanzania the adolescents were engaged in different group activities, such as singing, dancing, drawing, painting, pottery, sports activities and seminars. The seminars covered a variety of themes, for example, a seminar on managing stigma was attended by the researcher. In both countries the adolescents reported that the groups helped them in several aspects of life such as reducing stress when they had problems at home, and for some it was also the only place where they had friends. They gained knowledge about HIV, even advanced biomedical knowledge (as Pili demonstrated in the quote above about her CD4 count), medication, stigma, reproductive health, how to protect themselves from re-infection and others from infection, and also knowledge in terms of respect for others.

It was also a place where they could be open with each other and about their status. Kasigo (age 19) from Botswana explained that ‘in Teen Club we are just open to talk to everyone’, ‘….share the problems….’, ‘….to share something same….’. They met others in the same situation; they had fun together, and supported each other. Thobo (age 19) from Botswana expressed that ‘our team united us.’

The support groups also provided them with social skills to deal with the impact of stigma, as expressed by a boy in Tanzania:

‘The seminars which I get from PASADA and also the grieving session which I attended, have taught me how to handle myself and avoid self-stigma’ (Raul, age 14, Tanzania).

The importance of adolescents obtaining information on how to live healthily with ART was also articulated by healthcare staff. For example, one staff member in Botswana said that obtaining knowledge on how to adhere to ART is a prerequisite for adolescents to take control of their health:

‘The best thing we are doing here is information… when they are well kept with information they can do whatever they think in the right manner’ (health-care worker, Botswana).

These examples show that HIV services such as ART, counselling and support groups are important resources for the adolescents, enabling them to improve their health through knowledge and participation.

**To be disclosed to and to disclose to others**

Disclosure was important from both the perspective of being disclosed to, and to disclose own status to others. Knowing their own HIV status helps adolescents understand their life situation; by knowing the purpose of hospital check-ups and medication regimes, life finally makes sense. All the participants in the study had their status disclosed. However, several of the Batswana participants reported feelings of confusion and anger before they were disclosed to because they had to attend hospital check-ups and take medications without knowing why:

‘I used to find myself at the hospital without knowing what was happening’ (Henry, age 12, Botswana).

As Henry described, several of the Tanzanian participants experienced having to go for hospital check-ups without knowing why; they did not know that HIV was the reason that they sometimes had to go to hospital, they thought they were being treated for what they called ‘normal diseases.’ Some adolescents reported that they refused to take their medications, or used the medication incorrectly before disclosure because they did not know the real purpose for taking the medication or the way the medication should be administered. A Motswana girl explained about experiences of complacency, failing to see the purpose of repeatedly taking the same medication; she got angry and refused to take them. One Tanzanian girl described her experience as follows:

‘I took the ART for some months and I felt fine, so I stopped taking them because I felt I was no longer ill. My grandmother insisted I had to keep on taking...’
the medication. I used to run from her and complain about why I should keep on taking the medication.... When I was disclosed to in 2010...I felt bad and I hated and blamed my grandmother for not disclosing my status earlier. I regretted not adhering to the ART; I wished I was disclosed to earlier so that I could adhere to the ART and retain my energy' (Kisura, age 12, Tanzania).

In contrast, a Motswana girl explained that before she knew her status, she sometimes took additional doses of ART during the day if she had a headache or a stomach ache, because she had been told that the tablets would make her feel better. As the adolescents came to know their status and why they were on treatment, they were in a position to take control of their lives. All the adolescents in both Botswana and Tanzania wanted to know their status, even though many felt sad, shocked and lost hope at the moment of disclosure. When disclosed to this helped the adolescents to understand the importance of ART and how to adhere to treatment.

Most of the Batswana participants pointed out the importance of how disclosure helped them to live healthily and positively:

‘Because now I know my status and when I grow up I can take care of myself. If I didn’t know... I wouldn’t be caring about myself' (Marea, age 14, Botswana).

The Tanzanian adolescents did not explicitly mention being able to live healthily and positively as a result of disclosure, but they, like the Batswana participants, saw the importance of protecting themselves and others from transmission of the virus.

Knowing their status made the adolescents aware of what people around them thought about being HIV-positive. It gave them the choice of whether or not to disclose their status to others, and to consider to whom they would disclose their status. Our data show that adolescents are strategic about declaring their HIV status. Most participants would not disclose their status to people outside their family, like friends and other community members. In Tanzania most of the participants were advised by their caregivers not to tell others. Fear of stigma and other people’s lack of knowledge about transmission of the disease contributed to the adolescents choosing to keep their status a secret, as described by Kisura from Tanzania:

‘People in my neighbourhood do not know that I am HIV-positive, because I was told by my grandmother not to disclose my status to anyone in order to avoid stigma' (Kisura, age 12, Tanzania).

The adolescents in Botswana did not report that caregivers told them to keep their status a secret, but in most cases they chose to not disclose their status because of fear of stigma. Furthermore, two out of the three health-care staff interviewed in Botswana said they recommended children and adolescents to keep their status within their family until they grew older and were able to defend themselves from stigma:

‘I think they still have to keep it within the family... at that age they are still fragile minds... until the adolescent grows up, coming to a state where they can also defend themselves verbally' (healthcare worker, Botswana).

Due to the fear of being stigmatised, many chose to keep their status secret. However, a few of the participants in both Botswana and Tanzania had disclosed their status to some friends they considered trustworthy, and had positive experiences with this. They could get support and understanding from these friends; one girl explained that ‘I told because I felt better after I told them... so that they can understand' (Marea, age 14, Botswana). Furthermore, in Tanzania some of the adolescents also disclosed their status to their teachers, because they could provide them with social support in cases of stigmatisation at school.

What these findings suggest is that it was crucial for HIV-infected adolescents to know their HIV status. It provided them with opportunities to take care of themselves, to protect others, to choose whom to disclose their status to and to seek social support from.

Adolescents’ engagement with their social environment

Support from friends in the support groups and at school was mentioned by many of the participants, in both countries, and they seemed to thrive as a result of their friendships. However, the information they would share with their friends was different regarding which friends they would share with. With the friends in the support groups they were able to be open about their HIV status and share their problems because they were with others in the same situation. When we participated in these groups during our stay in the field, we got the impression that the adolescents really were enjoying each other’s company; they were chatting, laughing, dancing, playing and joking. Furthermore they seemed very confident to speak in front of each other and the adults that were present in the group, even when we, as researchers coming from the ‘outside’ were present. With friends they had not disclosed their status to; they would talk about issues other than HIV. A Tanzanian girl explained that being with her friends helped her:

‘I like staying with my friends because it helps me to avoid self-stigma, and also we are learning from each other, because we have different ways of understanding things' (Sara, age 14, Tanzania).

In Botswana the participants did not mention gaining knowledge from each other, but friends were the ones they could engage with in leisure activities and seek support from. Engaging in sports activities was important for many of the adolescents, and many of the Batswana participants said their sport made their day good. Taking part in sports activities included being part of a team or taking part in competitions.

In cases of stigmatisation or being bullied the adolescents would seek support from adults, like caregivers, social workers and teachers. This suggests that they were able to make use of the resources they had available in their environment. One teenager explained that she would seek help from teachers when experiencing discrimination from other students:

‘When I was still in school I used to face cases of discrimination from other students, which led me to tell my teacher to help me' (Kefiliwe, age 19, Botswana).
Adolescents from Tanzania would also turn to their teacher for help as mentioned in the section about disclosure.

As we noted initially, most adolescents in these studies had experienced stigmatisation. The participants from both Botswana and Tanzania thought the reasons for stigmatising included lack of knowledge about HIV and how it is transmitted. James from Tanzania explained how he responded to stigma:

'I usually ignore those who stigmatise me and I see them as fools, since they do not know what they are doing' (James, age 14, Tanzania).

James found strength in knowing the facts about HIV, and that he knew that those stigmatising him did this out of ignorance. One of the Batswana participants suggested telling the person stigmatising how it feels to be stigmatised. Some of the Batswana participants also explained that some of the people stigmatising didn’t know their own status, and might as well be HIV-positive themselves.

Many of the adolescents experienced support from both immediate and extended family. For most of the Batswana participants, their immediate families were often the most important source of support. For the Tanzanian participants the importance of their family was implicit in their statements as illustrated by Bibiana who described what happened when her aunt did not give her enough food:

'Sometimes my mother gave me her portion of food when I was given little; my mother could stay without eating and give her food to me to make sure I was satisfied' (Bibiana, age 14, Tanzania).

The participants from Tanzania also reported that family, both immediate and extended, was important when it came to following up treatment such as taking their medicines and caring for them if they got ill, paying school fees, bus fares, providing food and clothes among others.

Many of the Tanzanian participants had lost their biological parents and were living with their extended family; this also applied to some of the Batswana participants. For these the extended family was very important. One boy had lost his mother and explained how his uncle was a very important source of support for him:

'[My uncle] made that promise after my mother was buried; he told me — I’m going to support you in good and difficult times — and right now he still is' (Thobo, age 19, Botswana).

However, not everyone experienced support from their extended family when they needed it. Juma from Tanzania described his experience:

'After my father’s death we had a family meeting, where my family refused to let me to stay with them. They told me they would support me wherever I was, but it wasn’t so. Due to lack of support from my relatives, sometimes I had to walk long distances to school due to lack of bus fare. I wish my parents had left a will, it could have helped me' (Juma, age 14, Tanzania).

Due to lack of support from his extended family, Juma experienced difficulties in his everyday life.

Another source of support mentioned was religion. One participant mentioned religion was important to her as she believed that it could cure her illness:

'I am a good Christian and I believe that through God I will be healed, and I have been attending the healing sessions' (Bibiana, age 14, Tanzania).

Statements like the one above did not come up in the interviews with the Batswana participants; however, one boy said that he liked to go to church, because he found it was a good place to be.

The adolescents in the two studies had a range of different social relationships including with caregivers, immediate family, extended family, friends in their support groups, friends at school, teachers, healthcare staff and spiritual relationships like turning to God. We suggest that the adolescents’ engagement with their social environment helped them thrive in spite of challenges such as stigma.

Adolescents’ individual sense-making

Some of the Batswana participants reported that knowing their status was a strength to them, and they somehow managed to find confidence in their misfortune. One boy stated that ‘we have self-esteem because we know our status’ (Tebogo, age 19, Botswana). They pointed to those out there, who were stigmatising without even knowing their own status (as mentioned in the previous section), one girl saying that ‘at least I know my status’ (Kefiwe, age 19, Botswana). Juma from Tanzania explained how he thought a man was being punished for treating him in a bad way:

‘One of our neighbours pointed his finger at me, saying to the other people in the street…look at that child, he is HIV-positive….. Then I met him one day at PASADA, I couldn’t believe he was also HIV-positive. From then I believed that if a person does bad things to others, God will punish him, the way the man was punished. Unfortunately, that person is dead, but I am still alive’ (Juma, age 14, Tanzania).

Furthermore, both in Botswana and Tanzania, some of the participants said they knew it was not their fault they were HIV-positive, they knew they had been born with it and that they were not to blame: ‘I have been born with the… virus’ (Tabia, age 14, Botswana). This knowledge, and also knowing that the people stigmatising ‘did not know what they were talking about’, contributed to helping them deal with stigma. They believed that knowing their status they were better off than those who didn’t know as the knowledge enabled them to take care of themselves and know what they were heading for, compared to those who didn’t know.

All the participants in the studies had hopes and dreams for their future. School was mentioned as an important aspect for many of the adolescents, and many saw it as significant in order to be able to continue with further education. A Tanzanian boy explained:

‘I need support for school fees, as my aunt is not in a position to assist me with everything I need. I will appreciate if I get any kind of support, as I really want to study to fulfil my dreams’ (Raul, age 14, Tanzania).

Like Raul, all the other participants reported specifically on what they would like to do or to be in the future. Participants from Botswana mentioned a range of careers that they would like to pursue, such as teacher, doctor, policeman,
carpenter, singer and football player. One girl also had a dream of one day building a big house for her mother. The participants from Tanzania had similar goals.

In spite of challenges, most of the adolescents managed to make life meaningful as they had plans and hopes for the future. Many believed that they could overcome the obstacles they were facing, and some found strength in knowing their status and the reality that they were not to blame for being HIV-positive, they were born with it.

Discussion

Supportive context

All the participating adolescents knew their HIV-positive status and all were accessing ART and other support services. As stated in our introduction, only a small proportion of HIV-positive children in sub-Saharan Africa are told their status (Biadgilign et al., 2011; Kallem et al., 2011; Vaz et al., 2011) — making the participants in our studies an unusual group. Adolescents in our studies reported that disclosure contributed significantly to their adherence to ART, confirming the findings of other studies that have explored the links between disclosure and adherence (Bikaako-Kajura et al., 2006; Menon et al., 2007). The availability of ART has given adolescents the opportunity to live their lives fully and take control of their health and wellbeing. A recent study from Zimbabwe also found the availability of ART to contribute to a ‘normalisation’ of HIV, showing that it is possible to live a close to normal life in spite of being HIV-positive (Campbell et al., 2011). ART is accompanied by other services, such as counselling and support groups. In both our studies the social support groups provided by the treatment system seemed to enable the adolescents to form meaningful social relationships with other adolescents in the same situation, leading to a feeling of fellowship or being united as a group. Being part of a group seemed to make the adolescents strong and to create confidence. Furthermore, the support groups gave access to important information about issues such as HIV, ART, reproductive health and stigma.

We found that disclosure was a key factor for the adolescents in order to be able to access or make use of the different services that the treatment system could offer. For instance, in order to be a member of the Teen Club in Botswana the adolescents had to know their status. Campbell, Skovdal, Mupambireyi, Madanhire, Nyamukapa & Gregson (2012) report similar findings in Zimbabwe, where children were found to be more likely to actively participate in their treatment regimens when disclosed to. Recent studies recommend a systematic approach to inform and advise caregivers of HIV-positive children and adolescents about the disclosure process (Biadgilign et al., 2011; Kallem et al., 2011; Vaz et al., 2011). Our findings from Botswana and Tanzania support Menon et al. (2007) when they suggest that emotional and peer support could be facilitated by disclosure.

According to Petersen et al. (2010), adolescents with strong family support, and extensive social support networks, tend to cope better. In our studies from Botswana and Tanzania, family and friends were seen as important resources of support by the adolescents. Many of the adolescents were coping well in their situation, and we suggest that in these studies, similar to Petersen et al. (2010), it is evident that support from family and extensive networks contributes to coping.

Adolescents’ agency

Many of the adolescents in our studies actively accessed and used the resources (such as treatment services) available to them. As mentioned above, disclosure was a key factor in being able to effectively use many of the services the treatment system could offer, but we also found that disclosure could give life new meaning in the sense that the adolescents understood their life situation. It was commonly reported that before they were told about their status, they found themselves in a situation where they didn’t understand the reason for their medication regimes and hospital check-ups. After disclosure life finally made sense in the way that they found their treatment meaningful, and wanted to adhere to it to keep themselves healthy. Furthermore, many of them seemed to be able to apply the knowledge about HIV, ART and stigma to their own life situations and people surrounding them. The obtained knowledge enabled them to manage and to take control of their lives and to look positively towards the future.

In addition to making use of the available treatment system, many also actively sought support from friends, family, teachers, and healthcare staff. Several studies concerning disclosure to children and adolescents with HIV, report that one of the barriers to disclosure is that the caregiver fears that the child or adolescent will tell someone outside the family about his/her status, which could lead to stigmatisation (Vaz et al., 2008; Vreeman et al., 2010). Even though many of the participants in our studies chose to keep their status a secret, only disclosing to family members, some did choose to disclose their status to a few close friends. The rationale for this was that it felt good that someone knew, and for their friends to be aware and to understand their situation. Disclosing to some close friends did not lead to stigmatisation for these participants but instead to feelings of support and being understood. By disclosing to the adolescents they are given the opportunity to decide who outside the family, if any, should know their status. This could contribute to the adolescents being able to access social support also outside the family and the support groups within the treatment system. Another reason reported in the literature for not disclosing a child’s status, is the fear of being judged by the child (Vaz et al., 2008; Vreeman et al., 2010) but our findings show that what was important to the adolescents was that they knew they themselves were not to blame for their HIV status; this contributed to their ability to handle HIV stigma.

Resisting and coping with stigma

In spite of experiencing stigma, many of the adolescents appeared to have the necessary resources to cope with it. By knowing their status and being part of a treatment system the adolescents somehow managed to develop
strategies to deal with the challenges of stigmatisation. For example, the adolescents were in a position to decide who they would choose to disclose to. Sometimes the adolescents disclosed to teachers in order to seek their help when experiencing stigma and discrimination at school, other times they made a conscious decision to keep their status secret, which is a coping mechanism in its own right. This has also been observed by Thupayagale-Tshweneage (2010) who found adolescents in Botswana kept their HIV status and ART adherence a secret as a way of dealing with stigma related to HIV.

The knowledge they obtained through the treatment system helped them create a form of individual sense making, to know the reality, such as how the virus is transmitted, and get confirmation that being HIV-positive was not their fault, but something they had been born with. In addition, some of the adolescents found strength in knowing their own status. Knowing their status made them able to take care of themselves, but they also pointed out that there were people ‘out there’ who did not know their status, and that the ones stigmatising might be HIV-positive themselves without knowing. As a strategy to resist stigma, the adolescents felt sorry for those untested and in the dark about their HIV status. These findings echo a study in Zimbabwe (Campbell et al., 2012), which observed that adults on ART, in an attempt to cope with stigma, made a distinction between ‘us’ (the HIV-positive) and ‘them’ (those who do not know their HIV status).

Implications of the findings and recommendations

The findings from these studies underpin the importance of disclosing adolescents’ HIV status to them, as well as promoting access to treatment services including ART and social support. We have found that disclosure contributes to enabling adolescents to actively participate in their own treatment regimen; they gain important knowledge, confidence and a desire to adhere to their treatment, which furthermore enables them to cope with stress in life such as stigma and discrimination. There is much to learn from HIV-positive adolescents themselves regarding their own situation.

Study limitations

The Botswana and the Tanzania studies each had a relatively small number of participants and findings cannot be generalised. However, the phenomenological approach has provided insight into the lived experiences of HIV-positive adolescents, and found that the experiences and responses of adolescents from two different countries have been remarkably similar. This study has not explored how HIV-positive adolescents unaware of their HIV status and not on ART cope with stigma, or whether the age of disclosure and the length of time they have know their HIV status affect their ability to cope. These questions could provide a focus for future research.

Conclusions

The research shows that ART and disclosure opened up new opportunities for the HIV-positive adolescents to improve their health and enable them to live social and productive lives. Disclosure gave them a better understanding of their life situation and the desire to adhere to treatment. Disclosure made adhering to ART meaningful, and by adhering to treatment the adolescents managed to take better control of their lives. Through treatment and support services they gained detailed knowledge about their condition and how to manage their medication. Being part of a support group for adolescents in similar circumstances enabled a sense of openness and nurtured their confidence. Thus, the social context and the psychosocial resources it facilitated enabled HIV-positive adolescents to: 1) seek support from friends, family, teachers and healthcare staff in times of need, and 2) resist internalised stigma by seeing themselves as better off than those who have not been tested and are unaware of their HIV status.

Notes

1 Setswana is the predominant language in Botswana. Motswana refers to one citizen and Batswana refers to several citizens.
2 CD4+ T cells are the main components of the cellular immune system; CD4+ T cells are destroyed or impaired by the HIV virus, leading to immune deficiency.

Acknowledgements — We would like to thank all the adolescents who participated in the two studies and the staff at the various participating institutions for facilitating the research.

The authors — Vivian Midtte and Violet Shirima both completed an MPhil in international health promotion at the Department of Health Promotion and Development, University of Bergen, in 2012. This article is based on data collected for their master’s theses. Morten Skovdal is a community health psychologist writing about children’s health and community responses to HIV. He is with the Department of Health Promotion and Development at the University of Bergen and a visiting scholar at the London School of Economics and Political Science. Marguerite Daniel is an associate professor in the Department of Health Promotion and Development at the University of Bergen.

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