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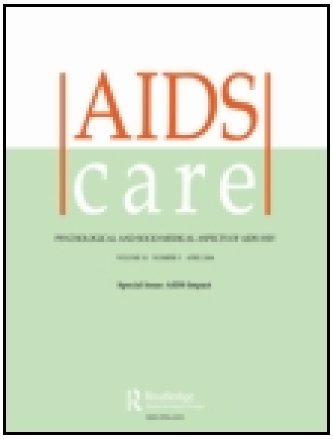

AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV
Publication details, including instructions for authors and subscription information:
http://www.tandfonline.com/loi/caic20

HIV serostatus disclosure and lived experiences of adolescents at the Transition Clinic of the Infectious Diseases Clinic in Kampala, Uganda: A qualitative study

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Published online: 14 Nov 2011.

To cite this article: Godfrey E. Siu , Sabrina Bakeera-Kitaka , Caitlin E. Kennedy , Aggrey Dhabangi & Andrew Kambugu (2012) HIV serostatus disclosure and lived experiences of adolescents at the Transition Clinic of the Infectious Diseases Clinic in Kampala, Uganda: A qualitative study, AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV, 24:5, 606-611, DOI: 10.1080/09540121.2011.630346

To link to this article: http://dx.doi.org/10.1080/09540121.2011.630346

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AIDS Care
Vol. 24, No. 5, May 2012, 606–611

HIV serostatus disclosure and lived experiences of adolescents at the Transition Clinic of the Infectious Diseases Clinic in Kampala, Uganda: A qualitative study

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(*Received 7 October 2010; final version received 28 September 2011*)

Most studies on HIV serostatus disclosure and adolescents focus on whether, how and when to disclose *to* adolescents their HIV diagnosis. Fewer studies have examined HIV serostatus disclosure *by* adolescents who know they are infected with HIV. This study presents qualitative data examining HIV serostatus and treatment disclosure practices and concerns of young people living with HIV in Uganda and the extent to which they are satisfied with current norms around HIV serostatus and treatment disclosure. We conducted two focus groups and interviewed 20 HIV-infected young people aged 15–23 receiving HIV care and treatment at the Transition Clinic in Kampala. Respondents perceived disclosure as a relationship encompassing both communication and self-conduct. Adolescents employed unique strategies to disclose their HIV status, notably joking to "test the waters" and emotionally prepare the other person before later disclosing in a more serious manner. Findings reinforce the idea that HIV disclosure is a process, not a one-time event. Interviewees anticipated both positive and negative outcomes of disclosure, including financial and emotional support, stigma, discrimination and rejection. They described a sense of violation of their autonomy when confidentiality was breached by third party disclosure, and also expressed fear of emotional distress for their loved ones. Although adolescents yearned to be in control of information about their HIV status and treatment, they have little space to call their own, and privacy is often compromised, especially because in traditional African settings, young people are considered to be dependents under the full responsibility of caregivers. Further exploration of disclosure outcomes and strategies specific to adolescents can help better tailor interventions towards youth. Antiretroviral therapy programmes should consider counselling for caretakers to appreciate and respect the privacy and disclosure concerns of their HIV-infected children.

Keywords: adolescents; HIV serostatus disclosure; antiretroviral treatment; qualitative study; Uganda

Background

The provision of antiretroviral therapy (ART) to children and young people living with HIV/AIDS (YPLHA) is a key component of Uganda's response to HIV (MoH, 2008). With effective and sustained treatment, many adolescents living with HIV will survive and be socially active.

Although HIV serostatus disclosure among young people is widely recognised as an important concern, most studies on HIV sero-positive status disclosure among this group, come from high-income countries, and most focus on whether, how and when to disclose to them their HIV diagnosis (e.g., Corneli et al., 2009; Myera, Moodley, Hendricks, & Cotton, 2006; Lesch et al., 2007; Vaz et al., 2008; Wiener, Mellins, Marhefka, & Battles, 2007). Other studies have examined the consequences of children learning their sero-positive diagnosis (Butler et al., 2009; Ferris et al., 2007; Mellins, Brackis-Cott, Dolezal, Richards, & Nicholas, 2002; Vreeman et al, 2010). Fewer studies have examined HIV serostatus disclosure by adolescents who know they are HIV-infected (e.g., Bakeera-Kitaka, Nabukeera-Barungi, Nöstlinger, Kekitiinwa, & Colebunders, 2008; Batterham, Rice, & Rotheram-Borus, 2005; Birungi, Obare, Mugisha, Evelia, & Nyombi, 2009; D'Angelo, Abdalian, Saar, Hoffman, & Belzer, 2001; Michaud et al., 2009). These studies collectively suggest that disclosure to parents, partners and peers remains low among HIV-positive adolescents due to stigma and fear of rejection.

For YPLHA who choose to disclose, it is unclear how disclosure to significant others actually occurs, and what they think about confidentiality and appropriate disclosure. The present study describes HIV serostatus and treatment disclosure practices and concerns from the perspective of YPLHA in Uganda, exploring their satisfaction with current norms around HIV serostatus and treatment disclosure.

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ISSN 0954-0121 print/ISSN 1360-0451 online

http://dx.doi.org/10.1080/09540121.2011.630346
http://www.tandfonline.com

Methods

This study was conducted among clients of the Transition Clinic of the Infectious Diseases Institute (IDI) in Kampala, Uganda. The Transition Clinic is designed to serve the needs of HIV-infected young people aged mostly 16–24. Individuals were included if they were aware of their HIV status and receiving ART. They were excluded if they were in poor health or unable to participate in interviews. Data collection occurred in May and June, 2009.

In-depth interviews

Two interviewers conducted in-depth interviews with 20 respondents (10 males and 10 females). The interview guide outlined general questions about life, HIV disclosure and treatment experiences, with appropriate follow-up questions and probes during the interview process. Audio-recorded interviews were conducted in the respondent's preferred language, Luganda or English, and lasted 40–70 minutes. Additionally, detailed field-notes were taken.

To avoid appearing judgmental, we did not explicitly ask respondents how they became infected with HIV. Therefore, we are unable to disaggregate responses by HIV transmission history. However, some respondents did discuss how they believed they became infected with HIV during the course of the interviews, so we believe our sample included both vertically and horizontally infected adolescents. Approximately 64% of clinic patients overall are horizontally infected (Muwonge et al., 2009).

Focus group discussions

Two focus group discussions with six respondents each were conducted, one for males and one for females. Groups were stratified by gender to allow for more comfortable and open discussions. Discussions were audio-recorded, lasting 85 and 55 minutes, respectively, and were conducted among in-depth interview participants.

Data analysis

Field notes were typed before audio transcriptions were completed and because they were richly detailed, field notes became the main data set. Transcripts were later completed and used for checking the field notes. The Luganda audio-records were translated into English, with meaningful Luganda phrases retained for illustrative purposes. Texts were read by two authors separately, each developing initial codes and emerging themes. Two team meetings followed to discuss and synthesise themes and sub-themes with emphasis on identifying patterns of relationships, commonalities and contrasts in the data.

Ethics

The study was reviewed by the Makerere University Faculty of Medicine Institutional Review Board and the Uganda National Council of Science and Technology. The IDI Research Committee provided permission to contact ART clients for recruitment. To ensure voluntary participation, a research coordinator contacted and briefed prospective respondents several days before the intended interview. All respondents provided informed consent or assent after being briefed again by researchers and assured of confidentiality and anonymity. A small transport compensation and refreshment was provided.

Results

Respondents

The 20 interviewees were purposefully selected to explore a broad range of experiences relating to ART and HIV serostatus disclosure and social life. Respondents included students, out-of-school youths, a market vendor, a hair stylist, parents and unemployed youth. Social status varied; while a few respondents had reasonable access to economic and social resources, the majority lived in challenging economic and social circumstances.

The median age of respondents was 19 (range 15–23). The majority (17/20) were single or double orphans, and most (12/20) were currently living with relatives, mostly grandmothers, aunts or older siblings. Five respondents could be described as household heads, with three of them living by themselves. Many of those living with relatives had a history of high residency mobility. Most respondents (18/20) had some schooling, but only seven were currently students, three at University. The majority of school dropouts were unemployed and worried about their future livelihood.

Meanings of HIV serostatus disclosure

We defined disclosure as "the voluntary verbal or written passing on of private and confidential information regarding one's HIV status and treatment to other people". However, from interviews and group discussions, various meanings of "disclosure" emerged. Many respondents perceived disclosure as a form of relationship. Female focus group participants in particular described disclosure as a relationship encompassing both communication and the various ways in which people living with HIV conducted themselves in the presence of others. They spoke of it as: "the way we relate with others who do not have the virus", "a way to communicate with others" and "the way you can conduct yourself with others who are not infected". Respondents also suggested that disclosure incorporates the environment in which this relationship occurs. One male interviewee said: "Disclosure is where you can feel comfortable with others". These accounts suggest that disclosure goes beyond the act of "telling" others about one's serostatus to a range of lived experiences.

How much to disclose

Respondents differed in their desired level of disclosure. These differences crossed gender lines. Overall, most respondents considered information about their HIV serostatus and treatment to be a private affair, but many felt disclosure to family members was unavoidable, so their HIV status should remain a family secret. However, a few respondents felt their HIV status should be public knowledge. These views varied and appeared to be linked with education level, length of time since learning their HIV serostatus and treatment; more educated interviewees and those on ART for shorter periods of time tended to prefer more restricted disclosure.

Positive and negative aspects of disclosure: support versus vulnerability

Many respondents believed that disclosure was a pivotal step in their lives and evaluated it in terms of benefits and risks. Each interview revealed an understanding of both health and social benefits of disclosure, including treatment support, social support and life opportunities. All respondents described how beneficial disclosure had been in their homes, especially in terms of support received from caretakers and other family members. This support included love, care and financial support (e.g., transport to the Clinic) and medication reminders. However, despite describing the benefits of disclosure, nearly all respondents had either experienced or feared other parties, such as family members, breaching their confidentiality by disclosing to others.

Disclosure strategies

Respondents employed various disclosure strategies that differed by contextual circumstances and the nature of the disclosee relationship. Respondents also suggested that disclosure is a skill developed over time.

Respondents said that disclosure can be a simple verbal act of "telling" other people about one's status, but it can also be accomplished implicitly through other mechanisms. Taking HIV medications openly, displaying HIV treatment documents and frequently visiting the IDI were described as implicit disclosure strategies. As one adolescent said:

> The vehicles that we travel that have on them the word 'IDI' call for attention, even those who may not be informed come closer to query. (Male interviewee)

Some adolescents, however, worried about "accidental" disclosure arising from taking ART in the presence of others or excusing themselves to take medicines in private.

> It (confidentiality) is not easy for me because it is the treatment that reports me. Even when a visitor comes, it is the treatment that reports me because I can not hide when taking the treatment. (Female interviewee)

In instances when direct declaration of sero-positivity was difficult or likely to provoke negative reactions, adolescents said that they had to be inventive and disclose through alternative ways. Jokes or analogies, typically suggestive of sero-positivity, were considered useful in aiding disclosure. In particular, jokes were used to gauge the potential reaction and psychologically prepare the disclosee, ensuring a soft landing if the adolescent eventually decided to tell, as the following extracts demonstrate:

> It [disclosing] can be shocking. So you first draw the person closer, make friendship with them before. *Kusaga*, meaning by making jokes! Here you tell the person at first as if you are just joking! Or making fun of the situation. So the person thinks that you are joking, when actually you mean what you say! For example, you can tell a friend that *fee twaffa dda*, or *akawuka katulyadda* (meaning, 'for us, we were infected with the virus long ago') in a joking way and the person will not take you seriously. Then later when he sees you take ARVs, you tell him, you thought I was joking last time. (Male FGD)
>
> There are times when someone is having a conversation and you feel they are actually taking about me. So you mention casually that *mwana ggwe embwa yannumma dda*! (Literally, 'you guy, I was beaten by a dog a long time ago', meaning, 'My friend, as for me,

> I was infected some time back'). I do this in a joking way so that I do not scare him too badly and he thinks I am joking. Even when I am going to the hospital for a clinic review he may still think I am joking. So when the time comes and you have to tell him he will find it normal. (Male interviewee)

Disclosure patterns and perspectives: trust, autonomy and power

Respondents were asked who knew their HIV and treatment status, how these person(s) came to know and how long after receiving their test results did any form of disclosure take place. Many respondents had independently disclosed their HIV serostatus to close family members, particularly caretakers such as aunts and grandmothers. Only two respondents had not disclosed to anyone.

However, when asked whom they thought was aware of their sero-positivity, most interviewees believed that far more people were aware of their HIV status than they had personally told. Being known to be ill and frequently visiting a health unit and third party disclosure were considered reasons for this. As one respondent said:

> By now many people know that I have HIV. All the friends of my uncle's wife know because she tells them. (Female interviewee)

Although disclosure by a limited number of third parties (medical providers, trusted family members and pastors) was appreciated, young people overwhelmingly resented unsolicited third party disclosure, and desired to be in control of the disclosure process themselves, as the following quote illustrates:

> I myself should take the initiative to tell others. Or I can pass through the counsellors or nurses because they can explain to others well. They know how to talk to people. It is their profession. (Female interviewee)

Despite this desire for autonomy, respondents acknowledged feeling powerless regarding disclosure. In numerous interviews, it became clear that the authority to disclose to other people had frequently been usurped by caretakers, often against the adolescents' wishes. A few respondents said that they wanted to disclose to others, but were prevented from doing so by their caretakers:

> Whenever they (relatives) would come to visit us, Mum would tell me not to tell them, saying they would laugh at me. She would ask me to tell some and not tell others. (Female interviewee)

Patterns of disclosure also seemed to reflect patterns of social and economic support, both actual and anticipated. Adolescents tended to disclose to specific individuals, particularly grandparents/aunts, who often were their caretakers. Others reported being scared to disclose because of their financial dependence on caretakers:

> I am going to keep on confusing them till when I am free, when I don't depend on any one; when I no longer ask someone for help, for example 500 shillings for water. (Male interviewee)

Challenges to disclosure

Fear of stigma and discrimination

Respondents were aware of HIV-related stigma in their communities. Fear of experiencing stigma and discrimination–along with the associated problems of rejection, abandonment, abuse and ostracism–was a commonly cited barrier to disclosure.

Protecting loved ones from distressing information

An important challenge to disclosure was the perceived need to protect disclosees, particularly loved ones, from distressing information or bad news. Both males and females talked about not wanting to subject their loved ones to psychological torture and viewed non-disclosure as a way to protect their carers. In particular, disclosing to a parent appeared painful:

> If you tell your parents who least expect you to be infected, they can get shocked and they die because all hopes he had in you have been halted. You know when the charcoal is on stove you know it is there and that it will one day be used, but when you put in fire then you know it is sure going to burn up. So instead of causing him such death you rather let him die without knowing anything. (Male FGD)

Challenge of telling partners

Many interviewees had partners at the time they tested for HIV. Some notified their partners of the test results and/or implored them to also be tested. Compared to females, males tended to value disclosure to other people over partners, current or future, expressing anxiety and fear of partner disclosure. In general, both genders emphasised how hard it was to disclose to partners and said assisted disclosure by trusted third parties may be desired.

Discussion

In this study, we examined the experiences, practices and concerns surrounding disclosure among adolescents living with HIV in Uganda. As children with HIV live longer, healthier lives because of ART, the issues described here will continue to grow in importance.

We used a qualitative design which allowed for exploration of commonalities and variations in experiences across participants in greater depth while minimising preconceived notions. Although the sample was diverse with regard to social characteristics, it was non-random and all respondents were receiving HIV care and treatment at a well resourced clinic in Kampala. Thus, applicability of results to YPLHA in other settings may be limited. However, we heard consistent responses from both interviews and focus groups and believe that data saturation was achieved. As a qualitative, exploratory study, our findings are not intended to be generalisable to other settings. Future quantitative research with a representative sample of adolescents could examine the frequency of specific experiences and perspectives. Additionally, qualitative research from different settings could identify commonalities and differences in disclosure processes.

Respondents' understanding of the meaning of disclosure varied. Disclosure was perceived as a broad concept that goes beyond the act of telling others about one's serostatus. It encompasses a range of lived experiences including the relationship and environment within which disclosure occurs. These findings suggest that youth may employ unique strategies to disclose their HIV status. One unique strategy described by respondents was joking to "test the waters" and emotionally prepare the disclosee before later disclosing more seriously. Understanding disclosure strategies that may be specific to adolescents can help better tailor interventions for YPLHA.

Our findings reinforce the idea that HIV disclosure is a process, not a one-time event (Cusick, 1999; Obermeyer, Baijal, & Pegurri, 2011). Kimberly et al. (1995) have described a six-step process of disclosure among HIV-infected women. In this process, women overcome the initial shock of an HIV diagnosis, assess whether they possess disclosure skills, identify potential disclosees, identify circumstances that might prevent disclosure, anticipate potential recipients' reactions and identify a motivation for disclosure. Further research could examine whether adolescents undergo a similar process of disclosure, and whether this process differs if the disclosee is a family member, friend or sexual partner.

When discussing how women make disclosure decisions, Sowell, Seals, Phillips, and Julious (2003) identified three themes–full disclosure, criteria for disclosure and emotional disclosure–which explained the extent to which women's descriptions of their decision-making processes reflected weighing benefits and costs of disclosure. Our findings show that adolescents anticipated both positive and negative outcomes of disclosure, including financial, social and emotional support, but also stigma, discrimination and rejection. Negative consequences resulting from disclosure have been documented in studies among adults, particularly women, in sub-Saharan Africa. Although infrequent, negative events do occur and include violence and abandonment (Grinstead, Gregorich, Choi, & Coates, 2001; Maman et al., 2003). Adolescents are at a different developmental phase and generally rely more heavily on social and financial support from others. While respondents in this study did not describe experiencing serious negative consequences of disclosure, they did feel their autonomy was frequently violated by third party disclosure. YPLHA also feared causing their loved one's emotional distress and sought to prevent this by non-disclosure, a barrier to disclosure for HIV-infected young people identified previously (Hoffman, Futterman, & Myerson, 1999). Rujumba, Mbasaalaki-Mwaka, and Ndeezi (2010) found that some Ugandan health workers are aware of adolescents' disclosure concerns, but their study, like ours, was conducted in leading urban HIV treatment centres. Further examination of disclosure outcomes among adolescents in rural areas and outside of care is needed.

Our findings also speak to family members and caregivers of YPLHA in Uganda. Despite efforts to keep information about their HIV status and treatment confidential, young people remained vulnerable to breaches of confidentiality by family members, friends and caregivers. Often, adolescents living with HIV yearn for privacy but rarely have it, especially in crowded homes and during the school day (Hoffman et al., 1999). Although many traditional African cultures consider young people dependents, findings from this study suggest YPLHA want and need to control their own HIV serostatus disclosure, with occasional assistance from trusted family members, medical providers and clergy. Programmes should consider scaling-up family counselling and pay greater attention to disclosure issues among family members of HIV-infected young people.

Acknowledgements

We thank all the adolescents who generously gave their time to participate in this study. We also thank our research coordinator Julian Nkuraija for contacting participants, research assistant Helen Najjuma for helping to conduct the interviews, and Stella B. Ssali for transcribing the data. Special gratitude goes to the Sewankambo Research

Scholarship and the Infectious Diseases Institute for financial support, and the Child Health and Development Centre (CHDC) for providing the office space where the interviews were conducted.

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