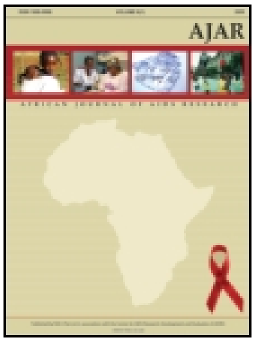

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An exploratory study of HIV-prevention advocacy by persons in HIV care in Uganda

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To explore how people living with HIV (PLHIV) and in care encourage others to adopt HIV-protective behaviours, we conducted in-depth interviews with a purposive sample of 40 HIV clinic patients in Kampala, Uganda. Content analysis was used to examine the message content, trigger events, and outcomes of HIV-prevention advocacy events initiated by the HIV clients with members of their social networks. The content themes included encouraging specific behaviours, such as HIV testing and treatment, condom use and non-promiscuity, as well as more general cautionary messages about protecting oneself from HIV infection. Common triggers for bringing up HIV-prevention advocacy information in a discussion or conversation included: wanting to prevent the targeted person from 'falling into the same problems,' wanting to benefit oneself with regard to avoiding re-infection, out of concern that the target would engage in higher-risk behaviour, due to observed changes in the target's health, and to convey information after receiving treatment at the clinic. The participants mostly reported positive or neutral responses to these advocacy events; negative responses were rare. Interventions to empower PLHIV to be agents of change could represent a new frontier for HIV prevention.

Keywords: Africa, communication, disclosure, qualitative research, risk behaviour, sexual behaviour, social networks

Introduction

People living with HIV (PLHIV) play a crucial role in reducing the spread of HIV as they are the primary vectors of HIV transmission. Recent HIV-prevention programmes have focused on counselling HIV-positive individuals to reduce their own risk behaviour as a way to limit transmission of the virus (Gerbert, Danley, Herzig, Clanon, Ciccarone, Gilbert & Allerton, 2006; Gilbert, Ciccarone, Gansky, Bangsberg, Clanon, McPhee *et al*., 2008; Samayoa, Anderson, O'Sullivan, Patricia, Pacheco, Matos *et al*., 2010). Other HIV-prevention programmes have focused on helping HIV-negative persons avoid infection (Abdool Karim, Sibeko & Baxter, 2010). Few HIV-prevention programmes have mobilised PLHIV to reach out to members of their social networks with HIV-prevention messages. The closest thing to an investigation of PLHIV working as 'change agents' for HIV prevention is a study by Paxton (2002) which examined how PLHIV engage in public HIV-status disclosure and advocacy at the community level (e.g. at schools, churches, community gatherings). However, such public advocates represent a small subgroup of PLHIV who are comfortable with disclosure in public forums within their community, and who are often employed to do so. Likewise, many HIV/AIDS programmes in Uganda have empowered some HIV clients to serve as 'expert patients' in the capacity of providing support to fellow clients and providers within the clinic setting. But it is not known to what extent this mechanism is being used to promote HIV-prevention advocacy in either public settings or within the private social networks of these empowered expert patients. Although the majority of PLHIV never engage in public disclosure and HIV advocacy, we have observed during our clinical work that most PLHIV encourage not only their sexual partners but also other people they know and love to get tested for HIV, to seek medical care, and to practice safer sex. Through qualitative research we sought to explore this apparently naturally occurring process of HIV-prevention advocacy carried out by HIV clients.

'HIV-prevention for positives' initiatives have received increasing emphasis from both practitioners and academics (Auerbach, 2004; Gordon, Stall & Cheever, 2004; Gordon, Forsyth, Stall & Cheever, 2005). These positive prevention interventions have typically focused on providing PLHIV with counselling, information, and support to enable them to reduce their own personal risk behaviour (Gerbert *et al*., 2006; Gilbert *et al*., 2008). Although these efforts are critical to limiting HIV transmission, so-called 'prevention for positives' can be expanded further to include interventions that facilitate PLHIV to advocate for and encourage HIV-risk reduction and protective behaviours among members of their family, friends and community. The personal life experience of living with HIV and receiving the health benefits of HIV treatment may position PLHIV to be the most credible voices for HIV prevention in their communities. Yet we are not aware of any published studies that have examined the potential for PLHIV to act as change agents for HIV prevention within their social networks.

Close variants of such interventions so far include HIV-prevention efforts that have successfully mobilised popular opinion leaders to advocate for HIV prevention within communities considered at-risk (Kelly, 2004; Maiorana, Kegeles, Fernandez, Salazar, Caceres, Sandoval *et al.*, 2007), and the mobilisation of injecting drug users (IDUs) to advocate for HIV prevention among other IDUs (Latkin, Mandell, Vlahov, Oziemkowska & Celentano, 1996; Latkin, 1998). There have also been peer-led HIV-prevention programmes among sex workers (Basu, Jana, Rotheram-Borus, Swendeman, Lee, Newman & Wiess, 2004) as well as HIV-positive peers trained to advocate for HIV prevention and risk reduction with other PLHIV (Raja, McKirnan & Glick, 2007). But we are unaware of any programmes designed to empower and train PLHIV to engage in prevention advocacy with members of their own social networks (both HIV-negative and HIV-positive).

This exploratory study set out to examine the extent to which HIV clients engage in HIV-prevention advocacy with members of their social network. Questions that we addressed included: What type of information, messages or encouragement do HIV clients provide to members of their social network? To whom in their network do they engage in such discussions with? What triggers these clients to engage in these discussions? And, what are the outcomes of their HIV-prevention advocacy efforts?

Methods

Study design and sample

A case-study design was used to collect data, from February to April 2008, using a semi-structured interview protocol. A qualitative approach was used as the research aimed to assess the processes by which clients engage in HIV-prevention advocacy — including their reasons for, the content of and the responses to advocacy communication — in order to better understand this rarely studied behaviour. The study setting was a large HIV clinic in Kampala, Uganda (the Infectious Diseases Institute at Makerere University), from where a convenience sample of 40 participants was recruited as they waited for their medical appointments. This sample size is generally considered sufficient for achieving saturation of relevant themes (Patton, 1990; Morse, 1994). A clinic staff member informed clients about the study and those who were interested were referred to the study interviewers to proceed with giving their consent to participate.

Interview protocol

The interviews focused on eliciting information about direct HIV-prevention advocacy whereby a person deliberately attempts to educate and encourage another person to engage in HIV-protective behaviour, such as how to avoid HIV infection or re-infection or spreading HIV, or how to seek HIV testing or care. Specifically, the participants were asked the following questions: 1) Have you ever spoken to someone about preventing HIV infection? 2) Tell me about the last time you talked to someone about HIV prevention. What exactly did you talk about? 3) What led you to talk about it? 4) What was the outcome of this discussion?

The interviews were mostly conducted in the participants' first language, and taped, transcribed and translated into English. The study protocol was reviewed and approved by the Research and Ethics Committee of the Faculty of Medicine at Makerere University and by the Uganda National Council of Science and Technology.

Data analysis

To identify the themes elicited in the interviews, we used text-management software (ATLAS.ti) to mark contiguous blocks of transcript text pertaining to the major domains of interest (i.e. the content of the HIV-prevention advocacy, triggers of the advocacy, and outcomes of the advocacy). We extracted all text associated with a particular domain and after printing participants' quotes on slips of paper, the team members sorted the quotes into piles based on their thematic similarities. We then named each thematic category and developed a codebook to describe each category.

Findings

The characteristics of the sample are presented in Table 1. The sample was equally divided between males and females; half were in the age group 18–35 and half were age 36 or above; 70% were self-employed in the informal sector; and, by the time of the interview, more than 80% had known their HIV status for more than two years, and more than 50% had spent more than two years in HIV care.

Targets of the HIV-prevention advocacy

Of the 40 participants, 39 reported having ever engaged in HIV-prevention advocacy with someone. These HIV clients had engaged in advocacy across all components of their social networks. The participants reported 104 distinct episodes of HIV-prevention advocacy; of their targets, 15% were their primary partners or spouses, 13% were their children, 31% were other family members or relatives, 27% were friends, and 13% were another category of person.

Table 1: Characteristics of the HIV clients interviewed (*n* = 40), Kampala, Uganda

Characteristics	*n* (%)
Females	20 (50)
Males	20 (50)
Age group (years):	
18–35	20 (50)
36+	20 (50)
Education level:	
At least some secondary education	15 (37.5)
Employment status:	
Formal employment	4 (10)
Self-employed (informal sector)	28 (70)
Unemployed	8 (20)
Time since knowing their HIV-positive status:	
>2 years	33 (82.5)
Time since joining HIV care:	
>2 years	21 (52.5)

Content of the advocacy

The content of the HIV-prevention advocacy reported by the HIV clients ranged from general messages that could be classified as cautioning others against getting infected with HIV, to more specific messages about seeking information, HIV testing and medical care, to ways to prevent HIV transmission (condom use, faithfulness, abstinence). During the interviews, the participants described 104 HIV-prevention-advocacy events; a total of 154 quotes with prevention-advocacy content were extracted from this, as some of the events had multiple types of HIV-prevention content.

General cautionary messages that did not seem to point to a specific method of preventing HIV infection were reportedly given to the targets in 46 of the 104 advocacy events. For instance, one participant explained how she advised her brother: *'Sometimes I find him in the bedroom and I counsel him; I tell him that my friend, don't move around, this world you see before you has a lot of sickness [HIV and AIDS].'* Another participant explained how he advised fellow youths: *'I do not speak very many words before I tell them* — You should protect yourself against AIDS. AIDS is quite painful, but it is us who invite it.*'* Another participant explained how he usually advised his workmates: *'I tell them that AIDS is for real. Everyone has to take care of themselves.'*

In 31 of the advocacy events, the targeted persons had been encouraged to use condoms. One participant explained how she advised her cousin:

> *'I gave him some [condoms] and told him* — You are young, you engage in unprotected sex which can lead you to getting infected; here are condoms, take them and whenever you engage in sex, use them to avoid HIV infection.'

Another explained how he advised people in his social network at large:

> *'I tell them that this condom saves life, and for some youths like the boda boda boys [commercial motorbike operators] I do not have enough time to sit down with them, so I tell them I have brought a lifesaver [condom], so they come and pick it.'*

Another participant had advised her son:

> *'I told him* — You are still young, but Satan can tempt you and you see girls who are beautiful, and you desire to have sex with them, but try to see that you use a condom.'

Another message was to encourage the targets to be faithful or non-promiscuous, which was noted for 29 of the advocacy events. One woman had advised a friend: *'I just told him that you are promiscuous but you get to know that the world now has problems in it.'* Another said she advised fellow women at a local mosque: *'I tell them that the world has now changed, things are hard…. If you have one partner that is the only one you should remain with.'* Another participant said she advised her female boss who was complaining about missing out on fun because of being married to a much older man: *'I told her that* — if God helps you not to get infected, you are better off sticking to your husband although he is too old.*'* Another participant said he regularly advised his friends: *'I usually tell them that those in marriage [should] remain faithful instead of having other affairs outside. If a side partner does not give you an unwanted pregnancy, he will infect you with HIV, nothing else.'*

Encouraging the targets of their messages to go for HIV testing or treatment was also a common message, given in 33 of the advocacy events. One participant had tried to advise her mother: *'I tell her to come [to the clinic] for testing, but she says* — I will go [for the test], I will go [for the test]*; she is still stuck at home.'* Another woman said that she often advised her daughter: *'I tell her every day, all the time, whenever I see her, to go and test for HIV.'* One participant had advised a friend who was claiming that recurrent malaria was disturbing her: *'I said if malaria is paining you, go and also do an HIV test, and get to know where you stand. But she said* — If they tell me that [I am] HIV-positive, won't I faint? *I told her there is not any problem; once they tell you that you are positive, you will know where you stand, and you will not be like someone who is there and they don't know their HIV status.'*

A rare focus of the HIV-prevention messages was to give encouragement to abstain from sex, as reported for only three of the 104 advocacy events. One participant said her friends would sometimes ask her to bring back free condoms from the HIV clinic: *'I usually tell them that I cannot bring them condoms because by doing so it would look like I am encouraging them to have sex.'* Another participant advised her children how to avoid HIV: *'I have three daughters. I told them the best way to avoid HIV is to abstain.'*

Triggers of the advocacy events

Of the 104 HIV-prevention advocacy events, the participants provided information about what had triggered or motivated them to engage in the discussion or conversation in terms of 78 events (thus for many events the participants were not able to identify a trigger). Some of the 78 events had multiple triggers. The trigger or motivation for engaging in the advocacy included the following: wanting to prevent the target from *'falling into the same problems as I am in'*; a desire to protect oneself or the target from the consequences of HIV infection or re-infection; because it *'came up'* during a conversation or discussion; the participant had observed the targeted person's potential for engaging in higher-risk sexual behaviour; the participant had noticed changes in the target's health; or it happened after getting treatment or information from the clinic.

Because it 'came up during a conversation/discussion' was a common trigger of HIV-prevention advocacy, reported for 16 of 78 events. These were largely described as informal conversations touching on different subjects affecting the participants and their targets in everyday life, including the subject of HIV. So, when the topic filtered into a conversation, the participants expressed how they would use the opportunity to convey an HIV-prevention message. For example:

> *'We had gone home for Christmas and we sat down to talk for a long period of time, and finally we ended up even discussing that HIV/AIDS topic. We were discussing about HIV/AIDS issues. They were telling me what they know about AIDS and I was also telling them what I know….'*

> *'It was at the neighbour's funeral, then one of the people around asked us how one can know that they are infected. This is how the whole conversation on HIV prevention began.'*
>
> *'Usually this talk comes up when we are doing our work of fixing tiles onto a floor of a building; usually there is not any other person around, but only those with whom I work.'*

An observed change in the target's health was another trigger of advocacy, as reported for 11 of 78 events. For instance, when asked what had prompted a participant to advise a friend to go and test for HIV after noticing changes in his health he said: *'He had AIDS-like symptoms.'* Similarly, another participant related:

> *'He was a very big man, but by the time he came back to the village from town, he had slimed. So, when I went to see him, he told me that malaria was disturbing him. Then jokingly I told him* — I know you well, you can't let a girl pass by you [without you hitting at her], but you are now claiming that is malaria! *For me, I was tested and I know my status.'*

One participant recommended HIV testing to a workmate: *'I observed him for some time and his health wasn't good.'* One woman said she often advised neighbours to go for testing: *'You may find that somebody is sick, and [other people] tell you so and so is sick. He/she has been treated but the sickness is not going away.'*

Having received treatment and information from the clinic was just as often a trigger of advocacy, as described for 10 of 78 events. One participant said he was prompted to give friends information:

> *'It was because of the treatment I was receiving, which made me think that a friend who may be in need of treatment can also be told to go and get it, how he should behave and how he should appear in public; that is how I wanted it to be.'*

Another participant was prompted to give information to his wife who was hesitant to seek HIV testing and treatment: *'Just like when I come from hospital I tell her what happened.'* Another participant advised his friends to go to gatherings for young people because, *'What made me tell them that is because one time the counsellor gathered us together here, they just invited us by phone, [just like] the way you invited me here, and they taught us [a number of things].'*

Many participants reported being motivated to engage in HIV-prevention advocacy because they didn't want other people to end up with the same problems they had, as reported for 22 of 78 events. One participant referred to the friends she'd advised to always use condoms: *'I don't want them to be like me.'* Another participant explained why he had advised his younger brother: *'Basically knowing how the world is, I may not tell him and he gets the same problems like the one I got.'* Another participant had advised her sisters to avoid HIV or to use condoms even if they were already infected: *'It's because of what I was going through due to my status that I decided to tell them this. I didn't want them to also go through the same.'*

Another common trigger for advocacy was the perception that some members of their social network were likely to engage in sexual risk behaviour, reported for 19 of 78 events. A participant who advised a friend to reduce the number of his sexual partners explained: 'He flirts with this [girl] and flirts with the other one; [and when] you look at [his behaviour], deep down you [get a feeling] he does not know how [HIV/AIDS] pains!' Because by then you would have [had firsthand experience of living with HIV].' Another participant explained why he told his son to concentrate on his studies and leave sex aside: 'We had been seeing him relating to different girls each time.'

Other common triggers of HIV-prevention advocacy were categorised as the desire to protect either oneself or others (including sexual partners or potential ones) from HIV infection, re-infection or other sexually transmitted infections (STIs), as reported for 21 of 78 events. For instance, one participant spoke about preventing re-infection with his own wife: *'Every time we are together we are just talking about avoiding re-infection so that we can live longer and be able to bring up our children.'* A participant who told her husband that they had to use condoms every time they have sex stated: *'I fear one thing: I will get pregnant.'* Another participant advised his girlfriend to remain faithful — and *'not to get other sexually transmitted diseases*.*'*

Outcomes of the advocacy events

Of the 104 HIV-prevention advocacy events, the participants were able to provide information about outcomes for 79 events, with some of these events having multiple outcomes. The outcomes included a full range of positive, neutral and negative responses to the advocacy messages. More than half of these events resulted in positive outcomes (i.e. the target acted on the information, changed their behaviour, or welcomed the message). Even so, a large portion of the responses indicated no change in the targeted person's behaviour, while in a few events the targets had indicated they were fearful of change. Finally, a small number of the events had been clearly negative for the participant.

When asked what the outcomes of their efforts were, the participants related 29 events wherein the targets had seemed to act on the information and/or had changed their behaviour. A participant who advised a friend to go for an HIV test reported: *'After testing, it was realised that he was HIV-positive…. He was treated and now he is healthy.'* Another participant had given free condoms to a cousin because she suspected that he was engaging in unsafe sex; as a result, she explained: *'He can now come to me and say* — Give me condoms, I am going [to meet a woman] and you told me to protect myself.*'* A participant who advised friends about HIV testing said: *'Previously they were living a risky lifestyle, but after talking to them, they changed. Whenever I am with them, we are always discussing HIV-related issues and not anything else.'*

A general welcoming of the advocacy message was reported as an outcome for 25 of 79 events. For instance, a participant described how their relationship had changed after advising a fellow student to take an HIV test: *'He came close to me; he even invited me to his graduation party.'* A participant who related how he would regularly advise fellow youths at church about HIV prevention said: *'I think my advice helps them a lot because they reach the extent of picking me up from home so that they can listen to my* *words.'* Another participant had disclosed to the congregation in the process of advising church members, and now — *'Whenever there is [an HIV] patient who needs advice, they come running for me.'*

According to the participants, it was a relatively common outcome to see no change in the target's behaviour, as described for 31 of 79 events. For instance, a participant who advised his friends about condom use stated: *'I think they did not take it seriously.'* Another who brought posters about HIV prevention to his workmates declared: *'It's like things are not put into action.'* Another participant who advised a neighbour to reduce his number of sexual partners believed, *'He failed to pick my advice.'* And one who directed his girlfriend to remain faithful stated: *'She picked [the message], but she failed to change her behaviour.'*

As a less frequent outcome, in eight of 79 events the recipients of the HIV-prevention advocacy reportedly expressed fear about their ability to change their behaviour and to face the potential consequences of these changes in behaviour. Fear as an outcome of the advocacy event was mainly observed among persons that had been advised to go for HIV testing, but were too scared of the test results. (Although this could fall under the theme of 'no change in behaviour,' it appeared to be a persistent outcome). In relation to this, one participant said he had advised a friend to do an HIV test but the target was 'just too scared' about it. Another participant had suggested that her mother go to a hospital for an HIV test, but the outcome was, *'She keeps saying* — I will go, I will go*; she is still stuck at home.'* Another participant had advised a workmate to be tested after seeing changes in his health; he described the impact of his words: *'For him he said that* — The moment they tell me like this [that I am HIV-positive], I think I will just collapse and die*.'*

Reportedly, there were very few negative responses directed at the participants after relating an HIV-prevention message. One negative reaction involved a participant who advocated for condom use to a family whose members were very religious; afterwards, he was rejected by the family: *'They said they did not want to hear about a condom.… They even chased me away.'* Another participant who advised an HIV-positive friend to adopt HIV-protective behaviours reported this response: *'She first remained quiet and then told me* — I didn't acquire the virus from a tree [and therefore, I don't see a problem with others acquiring it from me, because I was also infected by another malicious human being]*.'* But the participant said this same woman approached her later for advice on how to run a business and had also become friendlier.

Discussion

The findings suggest that most HIV clients engage in HIV-prevention advocacy with members of their family and friends, and that such advocacy extends to all components of individuals' social networks. The HIV-prevention advocacy carried out by the HIV clients had targeted a range of people in their social networks, such as spouses, children, parents and friends, but also people who were HIV-positive, HIV-negative, or of unknown HIV status. Numerous HIV-prevention interventions have focused on activating members of a community to be agents for behavioural change and HIV prevention, but this has largely been peer-focused (i.e. members of a specific at-risk population, such as drug users or sex workers, advocating to other members of the same population) (see Latkin, 1998; Basu *et al*., 2004). In contrast, our findings suggest that PLHIV may serve not only as change agents among their HIV-positive peers, but also within their larger social network and community as well, revealing a tremendous potential for PLHIV to make a dramatic impact on HIV prevention.

The content of HIV-prevention advocacy messages that the HIV clients gave their targets was often along the line of encouraging abstinence, being faithful to one's partner or using condoms — what is popularly known as the 'ABC' approach to HIV-prevention in campaigns that Uganda has successfully implemented in the recent past (Cohen, 2004). In the present study, however, abstinence was seldom the specific focus of the advocacy message. This conflicts with the position of many church leaders and conservative political leaders who are proponents of abstinence as key to controlling the spread of HIV; but these findings may support the position of others (who are involved in this debate with church leaders and political leaders) who argue that condom use and faithfulness are more realistic options for a sexually active population (Larraga, 1993; Okware, Kinsman, Onyango, Opio & Kaggwa, 2005; Murphy, Greene, Mihailovic & Olupot-Olupot, 2006).

Another common type of advocacy was to encourage others to test for HIV or to seek HIV care if infected. With all the participants being HIV clients, they may have been particularly motivated to encourage others to get tested and seek care and support services. For many clients, HIV care and antiretroviral therapy restores physical health and facilitates a return to productive daily functioning. During our work with HIV clients, we have observed clients who have been inspired and empowered by their health transformation to advocate for HIV testing and engagement in HIV care among people in their personal social network as well as the larger community.

In this study, a range of triggers were shown to have motivated the HIV clients to engage in HIV-prevention advocacy. Observing changes in a target's health or their potential to engage in sexual risk behaviour, and having received information from the HIV clinic (through counselling, posters, etc.) were all cues for the HIV clients to engage in advocacy. Whereas these triggers were naturally occurring in the participants' social environment, we suggest they could be reinforced through interventions to foster and empower HIV clients to engage in HIV-prevention advocacy at large. Interventions designed to train and mobilise popular opinion leaders as change agents may serve as useful models for such interventions (see Elford, Bolding & Sherr, 2004; Kelly, 2004).

The reported outcomes of advocacy for over half of the events were positive ones, with the targeted persons either being receptive to or welcoming the message or actually demonstrating a change in their behaviour. This highlights the potential for HIV-prevention advocacy on the part of PLHIV to have a significant impact on risk reduction and prevention of HIV transmission. This potential may be particularly strong in high-HIV-prevalence settings, such as in sub-Saharan Africa where most families may be somehow affected by HIV. If PLHIV can reach out with messages of HIV prevention to members of their social networks, which have been found to be relatively dense and interconnected (Green, Atuyambe, Ssali, Ryan & Wagner, 2011), the information transfer can be highly efficient and possibly result in a dramatic decline in risk behaviour and increase in HIV-related knowledge.

The participants described very few negative outcomes directed at them as a result of their HIV-prevention advocacy. Since the participants were asked to generally describe the outcomes of their advocacy messages, they may have been more inclined to mention the positive outcomes. Because we did not specifically ask about negative responses to their advocacy messages, they might have perceived that we wanted to hear about positive outcomes only. On the other hand, informing persons within one's social network to protect themselves against HIV infection, to not spread HIV, and to seek testing and treatment may be presumed to be done with good intentions, and thus may also explain the few negative outcomes that were reported.

It is important to consider what mechanisms are essential to engaging in HIV-prevention advocacy. Comfort with disclosure may be an important precondition if an HIV client is to effectively engage in advocacy within their personal social network. HIV-status disclosure enables a client to share their personal experiences of living with HIV and to reveal their sources of HIV-related information, such as their care providers or counsellors at the clinic — all of which can increase their credibility and result in the targeted person being more receptive to the prevention-advocacy message. We did not systematically assess whether the participants had disclosed their HIV status to the targets of their messages, or whether the targeted persons otherwise knew the participant's HIV status; however, other interview data regarding HIV-disclosure events among this same sample revealed that all but two participants had disclosed their HIV status to someone, and most had disclosed to several people in their social network (Ssali, Atuyambe, Tumwine, Sseguja, Nannungi, Ryan & Wagner, 2010). This general comfort with disclosure may be a key factor that enabled and motivated the HIV clients to engage in HIV-prevention advocacy.

Also, our interviews did not enquire about the stages the HIV clients might have gone through up to the point of engaging in HIV-prevention advocacy; however, we suspect that one's ability to feel comfortable discussing HIV and advocating for prevention is part of a process described by Sayles, Ryan, Silver, Sarkisian & Cunningham (2007) that emphasises the need for the individual to first gain a level of self-acceptance and then to reintegrate into normal societal functioning as a way of adjusting to the stigma of having HIV. We believe that such adjustment is critical to being psychologically ready and motivated to advocate for HIV prevention within one's social network.

Study limitations

There were a number of limitations to the study. The research relied on subjective reports from the study participants to ascertain the outcomes of their HIV-prevention advocacy with regard to the targets' responses and behaviours. Interviews with persons who were targets of the advocacy events would have provided a more balanced assessment of the outcomes. The findings cannot be generalised to all HIV clients as the sample included only clients who were interested in participating in the study and thus they may have been more likely to engage in HIV-prevention advocacy. Also, the small convenience sample of persons engaged in HIV care does not allow us to generalise the findings to all HIV-infected individuals in Uganda and other settings in sub-Saharan Africa. As noted above, the experience of receiving HIV care may specifically influence a person to engage in prevention advocacy, and HIV-infected individuals who are not in care may have considerably different attitudes and behaviours about advocacy as well as disclosure.

Conclusions

The findings suggest that HIV clients commonly engage in HIV-prevention advocacy with members of their social networks and that the responses to this advocacy are often positive. To the extent that HIV clients naturally engage in such advocacy, without external encouragement, suggests that HIV clients have the potential to serve as critical change agents for HIV prevention if this natural occurring process can be reinforced and facilitated with training that ensures that such advocacy provides accurate and effective communication to members of one's social network and community.

Quantitative studies focusing on the factors associated with engagement in HIV-prevention advocacy as well as the content of and responses to advocacy events are needed to understand how to promote effective HIV-prevention advocacy by HIV clients. Focusing on these factors can help us design better interventions by addressing the barriers that prevent HIV clients from engaging in HIV-prevention advocacy with people in their social networks.

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