"…No Stone Left Unturned:" How the Public Explains the Ugandan Success Story

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Abstract

We conducted a public poll to assess the public's perception about changes in HIV prevalence and its causes in a township in western Uganda. The main questions related to the declining HIV prevalence and its interpretation, as well as to the "Ugandan success story." The study used a qualitative methodology; we interviewed 68 citizens in eight focus group discussions. The majority stated that the HIV prevalence had declined in their town. Of those respondents, most cited behaviour changes related to Uganda's ABC strategy as their explanation of the declining trends. Those who said that a decline in HIV had taken place also stated that they believed in the Ugandan success story. Our study concludes that it is important to involve the public on important health issues such as HIV/AIDS in order to obtain more valid results by combining scientific findings with public/indigenous knowledge.

Introduction

Trends in the transmission of the Human Immunodeficiency Virus (HIV) in Uganda have been established mainly through HIV incidence assessments in two major cohort studies: in Masaka district, implemented by the United Kingdom–based Medical Research Council (MRC), and in Rakai district, implemented by the Johns Hopkins University, USA, and Makerere University,

Uganda. There is overall agreement that HIV transmission has decreased in Uganda, especially in the 1990s, and professionals and scientists no longer debate this point. In contrast, however, is an ongoing debate on which of the interventions or intervention components have been responsible for the decline. There is currently no consensus in the literature on precisely what kind of sexual behaviour change has occurred over what time period and how it has impacted HIV prevalence trends.

Many health professionals think that the most common behaviour changes to influence the decline in HIV infections in Uganda relate to the ABC (**A**bstinence, **B**e faithful and **C**ondom use) strategy. Numerous studies in the literature have investigated behaviour changes, including abstinence, later age of sexual debut, increased condom use and reduced number of sexual partners (faithfulness), and have appraised them all as public health approaches with proven effectiveness (Low-Beer et al. 2002; Hankins 1998; Mulder et al. 1994). However, a more recent study by the authors of the Rakai cohort studies (Wawer et al. 2005) has indicated that from the mid-1990s to the present, the main reasons for declining HIV prevalence in Rakai district have been increased condom use with casual partners and HIV-related mortality. Another explanation was provided by Green et al. (2006). They postulate that a high level of fear, combined with the public's knowledge that they could do something to avoid being infected (achieved through education on the ABC strategy), resulted in optimal conditions for behaviour change. "Fear appeals," according to these authors, were strongest during the early stages of the national response (1986–1991), which coincided with a major decline in HIV prevalence.

Several other authors recognize that personal experiences, stories and social networks are important in traditional societies such as Uganda to disseminate knowledge (Parkhurst 2002; Macintyre et al. 2001; Whitworth et al. 2002; Okware et al. 2001). These authors have stated that sexual behaviour change can be the consequence of reasons other than intervention programs – for example, as a consequence of friends and relatives dying of HIV/AIDS, something experienced by virtually every Ugandan. Allen (2006) argues for further investigation into such phenomena, stating that since much of the information presented to explain HIV trends is quantitative, data based on qualitative "anecdotes" often go unrecognized by the scientific community. He further states that scientific discussions are very valuable but not complete and comprehensive if one source of information, for example, the public's opinion, is missed (Allen 2006).

The discussions about the Ugandan success story in HIV/AIDS prevention took place almost exclusively in the scientific and professional community, with little interaction with and input from HIV patients, their families and the public at large. A MEDLINE search for articles where patient or public input was systematically sought to help interpret HIV/AIDS-related study findings and phenomena (such as trends in HIV prevalence) revealed no published information from Uganda. The only publication we found in our literature review was a study from the Rakai project, where the target population was asked how they perceived the benefits of the research results to their welfare and local development (Thiessen et al. 2007).

Background Information

Fort Portal is a township and the district capital of Kabarole district, located in western Uganda. Its population is around 40,000. The town's economy has increased substantially over the past years. Fort Portal has three hospitals and is home to the Kabarole District Health Department. There are five primary and three secondary schools, providing schooling from primary one level to secondary six. The main trading goods are agricultural produce, including tea. Data from Fort Portal showed that HIV-1 prevalence declined significantly in young pregnant women, from 33% in 1991, to 9% in 1997, and then to 6% in 2004 (Kilian et al. 1999). HIV prevalence in Kabarole district is currently 11.6% in the sexually active population (Uganda Communication Commission 2003) and is higher than the national average of 6.3% (Uganda Ministry of Health 2006).

Research Questions

The study aimed to answer these three questions:

What are the public perceptions of the trends in HIV prevalence in Fort Portal town over the period 1991–2004?

Is the public in Fort Portal town aware of a declining trend in HIV prevalence, and how does it explain this trend?

Does the public know about the "Ugandan success story," and what does it think about it?

The study was conducted from September to December 2005 in Fort Portal. It was part of a larger investigation of HIV prevalence trends over 14 years, using quantitative and qualitative methodologies. Both components were part of an MSc thesis research project by the first author. The quantitative part consisted mainly of analyzing trends in HIV-1 prevalence surveillance data of pregnant women attending antenatal clinics over a 14-year period (Kipp et al. in press). The component presented here is the qualitative part of the study. The study was financed through the Fund for Support of International Development Activities (FSIDA), University of Alberta, Edmonton, Canada.

Methods

Sample Selection

Participants for the focus group discussions (FGDs) were chosen based on their potential to provide insightful thoughts, comments and opinions on HIV prevalence trends. Participants were selected from several groups: (a) professionals (working in areas of civil service, education, police, etc.), (b) citizens of middle socio-economic and educational status, (c) traditional healers, (d) health professionals, (e) youth, and (f) members of the HIV Post Test Club of Fort Portal, a support group for persons with HIV. Eight FGDs were conducted, each with an average of 7 to 12 participants, with a total of 68 participants. Women and men were equally represented. FGDs ranged from 45 to 90 minutes in duration and were held in a conference room in Fort Portal. The site was chosen for its neutrality, for ease of access by participants and for a private, quiet atmosphere conducive to discussion. As remuneration, participants were given drinks and snacks at the conclusion of the discussion and a small stipend (around USh 5,000, or US 2 dollars) to cover transportation and other related expenses.

Study Instrument

A list of topics with questions relevant to the research themes was developed with input from local researchers and health officials. A funnel method was used to develop questions, beginning with general questions and leading to a more specific discussion to achieve a balance between obtaining information that suited the researcher's interests and allowing respondents to influence the flow of discussion. Each group was asked a common set of questions about Uganda's HIV trends, its HIV/AIDS success story and reasons for HIV trends. Examples of these questions include, "What do you think are the trends of HIV infection in Fort Portal?" "What type of behaviour change do you think was responsible for these trends?" "Have you heard of the Uganda success story and what does it mean?" "Where have you heard this?" "What is your definition of the Ugandan success story?" (For example, fewer people are dying, anti-retroviral drugs are freely available, people are living longer, new infections are occurring less frequently, people are widely aware of HIV/AIDS.) "Do you agree that Uganda is a success story? Why or why not?" "Are you satisfied with your information on HIV/AIDS including prevalence trends?"

Data Collection and Analysis

FGDs were conducted by the principal researcher and two research assistants fluent in Rutooro, the local language. All FGDs were audiotaped using both digital and analog tape-recorders. In addition, a research assistant manually recorded notes. The facilitator introduced the main themes to be discussed and the purpose of the discussion. Following this, participants were asked to discuss

the themes. Probing was used throughout to encourage participants to elaborate, in order to follow up on statements and to achieve a suitable depth of knowledge and insight.

Transcription took place after completion of each FGD. When FGDs were conducted in English, the principal researcher completed the transcription. When they were conducted in Rutooro, the primary investigator worked with a translator who transcribed a verbatim account of the group discussions directly into English. Data from FGDs were verified in several ways: Firstly, we used probing and verification questions during discussions to ensure participants' words and meanings were understood correctly. For example, a verification question could consist of the researcher repeating a participant's comment back to him or her in the form of a question requiring a yes/no answer. This kind of probing helped clarify participants' opinions or attitudes on the issues being discussed. Secondly, the audio recordings and the notes taken during the FGDs were cross-checked to fill gaps in the discussion. Finally, during transcription, culture-specific wording and meanings were defined and explained to the primary investigator by the transcriber.

Data analysis of FGDs followed guidelines set out by Rothe (2000). After transcription, an overall reading and surface analysis of the transcript was completed. During this first reading, general themes and possible sub-themes were identified. Following this initial reading, themes and sub-themes were arranged into groups whereby related concepts were placed together under overarching themes. Codes were assigned for each theme and sub-theme. Transcriptions were then organized into Word tables by question and response sets. The coded statements were divided up according to theme of answer, group and gender responses to each question. Frequency of responses for each applicable question was obtained, as well as frequency of themes given in responses.

Ethical approval

The study was cleared by the Ethical Review Board (Panel B) of the University of Alberta. Approval in Uganda was sought from the Uganda National Council for Science and Technology and from the District Health Officer, Kabarole district. We obtained informed consent from all study participants prior to the interview. For this purpose, participants were given or read an information letter outlining the purposes and implications of the study and clarifying the voluntary nature of their participation. They gave consent either by signing or thumb-printing the consent form prior to the interview. No names of interviewees were recorded. Before beginning the discussion, we ensured that participants understood their statements were to be audiotaped.

Study results revealed that several overarching themes had emerged from the questions asked during the discussions. Each theme and linkages between themes were found, reflecting the interdependence of issues. These themes are presented as the headings in this section.

Awareness of Declining HIV Trend Is High

In general, participants felt that HIV prevalence had decreased in Uganda since the early 1990s. However, some participants, especially females, felt that it had increased or stayed the same. Explanations for decreasing HIV trends ranged from citing the government of Uganda's strong political response to AIDS, which included a multi-sectoral AIDS control strategy to HIV programs organized by non-governmental organizations. This is apparent in the following quotes:

> (Male Citizen): "…because the government and churches and education institutions have done a big job to see that they bring awareness among the communities. This has been a big step forward. You heard about the Catholic Church Bishops from all over Africa [holding] a two-week conference in Uganda to fight against this thing."

> (Male Professional): "Because, uh, the government policy is very clear on AIDS, to an extent of making a secretariat in Kampala, fully funded, up to…the District level."

> (Female Professional): "For instance, there are even policies, the government has come in to

enforce in schools…when we are going with the…sports women and men together…the girls should go with senior women, a lady, there must be a lady to accompany them."

Behaviour change, usually in the context of the ABC strategy, was cited emphatically by participants who said that HIV prevalence had declined, as shown in the following statements:

(Male Professional): "At the end of the day, people were aware that AIDS is there, and they have tried how to control themselves, at least, those one who are reckless, they go they use condoms. Others, I think in the schools they are encouraging abstinence, they are doing that one, and they are seeing good results so far."

(Male Youth): "This disease has gone down because they have tried to fight against it in different ways. Because we hear them encouraging us, saying that you as youth when you want to involve yourselves in such activities, you should use condoms or you should abstain."

Positive Sexual Behaviour Changes Have Taken Place in Youth

Despite the challenges of changing youth behaviour raised in the FGDs, many participants (both youth and adults) felt that youth were changing their sexual behaviours in a positive way. The dominant behaviour changes that participants reported were related to Uganda's ABC strategy. Others included postponing first sex and increased uptake of voluntary counselling and testing for HIV (VCT), as documented in the following responses:

(Female Youth): "If the boy is not faithful to me then I can decide to abstain or if I get another one I will tell him to use a condom."

(Female Professional): "…the youth are really moving on a positive trend, because these are the virgin people who have been, who are aware...of the causes, eh? And these are the very people who are using the condoms."

(Male Health Professional): "…in that the youth still have play [inaudible] sexual relationships but then, they do it in a safer way by using condoms. And they think with the [inaudible], most of the condoms that are being consumed are being used by youth."

(Male Professional): "Most cases the girls thought that to make a boy happy, a man happy is through sex intercourse. But today, they say no. They are assertive. And that's a real achievement at best."

Peer groups were also seen as a potentially positive influence on behaviour change:

(Female Professional): [Regarding VCT uptake] "Because the youth, they are vigilant, they are energetic, they are inquisitive, and they are determined. And because of that, once you have told them something, they want to go in and find out, are determined to do that thing. And when they go, they disseminate the information to their peer groups, the youth. The other youth, because of the vigilance they have, they feel they are determined to go and teach others."

The "Ugandan HIV/AIDS Success Story" Is Known

A definition of the Ugandan "success story" (that Uganda has successfully lowered its HIV prevalence) was given to all participants prior to discussing this topic. Virtually all had heard of and agreed with the story. Participants were then asked how they themselves defined the success story. Elements of Uganda's AIDS control program dominated participants' definitions:

(Male Citizen): "Another one, I can see that the success is there, there is a provision of getting these anti-retroviral drugs which can reduce the disease up to a certain period where people can buy it at [a] manageable price."

(Female Citizen): "For me the success story I am seeing in the fight against this disease is that the government has provided many free drugs and they have told everybody to go for [a] check-up in order to know their HIV status, and in many cases patients are provided with some free things to assist them and to assist orphans."

(Female Professional): "It is a cutting, a cross-cutting issue. And, multi sectors, so it is called a multisectoral, cross-cutting issue. So there is no way we shall leave stones unturned, which Uganda has done… and that one has brought success."

Challenges to the Success Story

Although virtually all participants agreed that Uganda has been "successful," most felt there was still a lot of work to do to reduce HIV/AIDS. Participants' view was that behaviour change had occurred slowly, despite the efforts of the Ugandan government and its partners in HIV/AIDS control. Social issues such as poverty, polygamy, prostitution and stigma were also cited as challenges to Uganda's continuing success in lowering its HIV prevalence.

(Female Citizen): "Therefore Uganda as a country has played its part in informing the public on preventive measures, except the problem is still that people are ignorant."

(Female Citizen): "…it has provided assistance to almost everybody, except that the people have refused to make a choice on what to do, and [there] are still many who have refused to go for [a] check-up, up to now."

(Male Health Professional): "I think also that it is one thing to give information, because we have reached many people, and it's quite another to change behaviour. You know AIDS is very much around here. So many people might have that information, but have not yet all taken [inaudible]. It's dreadful."

One respondent raised an interesting point on the dilemma of informing the public about the positive changes in HIV prevalence trends:

(Male Health Professional): "And it has not been actually culture to disseminate [to] a group and say, 'look, HIV problem is becoming less,' because that would make people reckless. So [inaudible], we have to keep saying the problem is big, and we must keep alert, so that you're not caught."

This statement was reiterated by a few health officials, who found it "dangerous" to communicate the "true" declining trend of the HIV prevalence to the public.

Discussion

Involving the public in the research process and the interpretation of research results is not new. In 1999, Popay et al. advocated that lay knowledge should be recognized more and that the understanding of research results is more robust and holistic if lay knowledge is considered (Popay et al. 1999). Involving aboriginal populations in research has become standard practice in Canada, where local people are consulted in research design and the interpretation of results (Stevenson 1996). Yet public involvement in public health research has been rarely undertaken in many developing

countries. To the best of our knowledge, no attempts to capture public knowledge on the interpretation of HIV/AIDS issues have been made in Uganda.

One important finding of our study was that the majority of respondents believed HIV prevalence had declined in Fort Portal and that the decline was most likely a result of sexual behaviour changes. This corresponds very well with two of our previous studies from the same area: the first described the declining HIV prevalence as a consequence of increased safe-sex behaviour (Kilian et al. 1999); the second described the change in sexual behaviour as largely due to increased condom use, and to a lesser extent to increased abstinence and a reduction in numbers of sexual partners (Kilian et al. 2007). Our study indicates that the majority of participants who recognized the importance of HIV infection rates were in the young population, a finding that reflects and confirms research from this area that young people had the highest HIV infection rates.

The most important result of this study was that the majority of respondents thought the sexual behaviour change which they observed was best explained by a multi-method approach to HIV prevention such as ABC and not by an approach emphasizing abstinence as a particular method over other methods such as condom use. The exact mechanism on what caused the declining HIV infection rates (and the Ugandan success story) has been controversial in the scientific community. While some authors advocated for abstinence only programs, others opted for a multi-method approach to HIV prevention programs (Singh et al. 2003; Cohen 2004; Wilson 2006). These authors claim the decline in HIV prevalence in Uganda is best explained as a result of the "full ABC" approach versus just the "A" approach. This strongly reinforces that abstinence alone is not a satisfactory explanation for a declining HIV prevalence. Participants' responses to this question disagreed with the assertion that an abstinence-only message is required.

One participant commented on the danger of informing the public about improvements in the HIV/AIDS situation. He feared that people hearing the success story would fall back into unsafe sex and may cause a new spread of HIV. We heard this argument informally several times during our study, mainly from health professionals. In our opinion nothing can be more wrong: Firstly, there is no scientific evidence at all to suggest that this would happen, and secondly, healthcare professionals have a moral obligation to tell their clients and the public the truth about changing trends relevant to important infections, including HIV/AIDS. The main concern is that if the public is not aware of improvements in the HIV/AIDS situation as a consequence of health-team interventions, it may view the interventions as not effective and therefore not credible. This could undermine the work of the health teams and could result in their losing the trust of the population, which in turn may lead to their health messages being rejecting or ignoring.

Limitations

(1) This was a qualitative study; therefore the generalizability of the study to a larger urban population is not possible; (2) As sensitive issues were discussed, we cannot exclude that a social desirability bias may have occurred; and (3) We also cannot exclude that small errors due to language barriers occurred in spite of careful translations from English to the local language Rutooro and vice versa.

Conclusions

Our study highlights that there is merit in validating scientific findings of studies with knowledge from the public to help clarify the divisive controversy that surrounds the interpretation of the Ugandan success story. The ongoing controversial discussion by some professionals and scientists on what constitutes the Ugandan success story emphasizes the need to learn more about all pieces of the puzzle. Our study data from the opinions of the public support what informed professionals have said all along: the declining HIV prevalence in Uganda is likely explained best by multiple changes in sexual behaviour (ABC) and not by abstinence only. Public knowledge and perceptions of these trend changes in the HIV/AIDS epidemic are an important contribution to the overall interpretation of the Ugandan success story. The Kabarole Health Department needs to endorse

public information about their HIV/AIDS control program and disseminate the epidemiological situation of the HIV/AIDS epidemic regularly. Perceptions by a few health officials that providing the correct HIV/AIDS trend data to the public is "dangerous" because they believe it may stimulate high-risk sexual behaviour is not warranted and ethically not defensible. We believe that withholding information of such importance may backfire on the long run in such a way that the public will lose trust in their healthcare system, with negative consequences.

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