

## *Full Length Research Paper*

# **“Public perceptions of HIV prevalence trends in a municipality in Western Uganda”**

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Accepted 19 October, 2009

**In order to assess the public's perception of the declining HIV prevalence in a township in western Uganda and its causes, a cross-sectional household survey of 252 randomly selected citizens was conducted in 2005. Survey questions related to the declining HIV prevalence documented in this location and its interpretation, as well as to trends in AIDS-related deaths and stigma. Forty-five percent of all interviewees stated correctly that the HIV prevalence had declined in their town. Out of those, 75% of the respondents cited behaviour changes related to Uganda's ABC (abstinence, being faithful and using condoms) strategy as their explanation of the declining trends (condom use 38.1%; faithfulness 27.4%; abstinence 23.0%). Also, 68% of respondents said that they believe in the Ugandan “Success Story.” The conclusions of this study are that it is important to acknowledge the public's opinion for the explanation of trends in communicable disease control including HIV infection.**

**Key words:** HIV-prevalence, public opinion, trends, rural Uganda.

## **INTRODUCTION**

The “Ugandan Success Story” in limiting the spread of the Human Immunodeficiency Virus (HIV) has been corroborated through HIV incidence assessments in cohort studies and HIV prevalence studies in pregnant women attending antenatal care (ANC) clinics. For example, the government data on ANC attendees in the age group 15 - 19 years showed a decline of the HIV prevalence from 33% in 1991 to 9% in 1997 in western Uganda (Kilian et al., 1999). National sero-surveys undertaken by the Ugandan Ministry of Health have confirmed a significant decline in HIV prevalence, from 18% in 1992 to 6% in 2004 - 2005 (Ministry of Health, 2006). Interpretations of these declines, however, are not without controversy. Both the extent and reasons for the HIV prevalence decline has been debated widely in Uganda by the scientific and professional community.

The most common explanation thought by many health professionals to have influenced the decline in HIV infection in Uganda is sexual behaviour changes relating

to the “ABC” strategy (A = Abstinence, B = Being faithful, and C = Condom use). Numerous studies in the literature have supported different behaviour changes, including abstinence, later age of sexual debut, increased condom use, and reduced number of sexual partners (faithfulness) and have appraised all of these as public health approaches with proven effectiveness (Low-Beer and Stoneburner, 2003; Hankins, 1998; Mulder et al., 1995). However, a more recent study by the authors of the Rakai cohort studies (Wawer et al., 2005) has suggested that partner change rates have stagnated or are increasing, finding that from the mid-1990s up to the present, the main reasons for the declining HIV prevalence in Rakai district have been increased condom use with casual partners, and HIV-related mortality. Fear of getting HIV/AIDS has also been implicated in the declining trend of HIV (Parkhurst, 2002; Macintyre et al., 2001; Whitworth et al., 2002; Okware et al., 2001). Allen (2006) provides an argument for further investigation into such phenomena, stating that much of the information presented to explain trends in HIV prevalence is quantitative, and that data based on qualitative ‘anecdotes’ often go unrecognized by the scientific community.

These examples show that discussions around Uganda's

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success in HIV/AIDS control took place almost exclusively in the scientific and professional communities with little interaction and input from HIV patients, their family members and the public at large. A Medline search for articles where input from patients or the general public was systematically sought to help interpret HIV/AIDS-related study findings and trends in HIV prevalence revealed no published information about this topic from Uganda. Scientific discussions are very valuable, but not complete and comprehensive if one perspective on that information is missed (Allen, 2006). Anecdotal and qualitative information can be vital in understanding the public response to public health campaigns, and should be actively sought when evaluating and targeting such campaigns.

In order to include the broader views of the public into the discussion of research results about the declining HIV prevalence and the "Ugandan Success Story", we conducted a public polling survey in a township in western Uganda. This survey aimed at answering the following three research questions:

- (1) What are the public's perceptions of trends in HIV prevalence in Fort Portal town over the period 1991 - 2004?
- (2) If the public in Fort Portal town is aware of a declining trend in HIV prevalence, how does it explain this trend?
- (3) Does the public know about the "Ugandan Success Story" and what does it think about it?

This study was conducted between September and December, 2005 in Fort Portal. It was part of a larger study using quantitative and qualitative methodologies. The quantitative study component presented here was part of the MSc thesis of the first author.

## METHODS

A cross-sectional household survey consisting of a semi-structured interview of mainly closed questions was used with 252 participants. Only respondents over the age of 18 years were interviewed. Efforts were made to include equal numbers of males and females in the study.

### Description of the area under investigation

Fort Portal is a township of around 40,000 people, and it is the capital of Kabarole district, located in western Uganda. Fort Portal has three hospitals and is home to the Kabarole District Health Department. There are five primary schools and three secondary schools, providing schooling from primary level one to secondary level six. Main trading goods are agricultural produce and tea, and the agriculturally-based economy of Fort Portal has increased substantially over the past few years.

HIV/AIDS has seriously affected Fort Portal and Kabarole district. A national and district-level HIV/AIDS program was established in 1990 which included a public education program on HIV/AIDS as part of its core elements. In 1991, a system of sentinel surveillance of HIV infection in pregnant women attending ANC clinics was established. This anonymous, unlinked surveillance program was set up

according to a national strategy with guidelines developed by the Ministry of Health of Uganda. The data from Fort Portal, the urban site, showed that the HIV prevalence in pregnant women declined significantly from 33% in 1991 to 9% in 1997 and then to 6% in 2005 in the younger age groups. In the older age groups (above 30 years) this trend was less pronounced. Results from another study from the same area that measured trends in sexual behavior of secondary school students from 1994 - 2001 found increased condom use and improved safe sex behavior in this young population (Kilian et al., 2007). To date the HIV prevalence in the general sexually active population of Kabarole district is still around 10% which is higher than the national average of 6% (Ministry of Health, 2006).

### Development of interview-administered questionnaire

As no standardized questionnaire was available for this study purpose, a questionnaire was developed by the research team. The survey questionnaire was revised with input from Kabarole District health officials. The questionnaire was pre-tested in six adult persons with minor revisions made after pre-testing. The final questionnaire comprised of 54 questions. Most questions were closed, with a few open-ended questions which were later coded. Eleven questions consisted of demographic information such as age, sex, marital status, housing type, income, religion, and education. Twelve questions included basic knowledge of HIV/AIDS, its causes, symptoms, modes of transmission and prevention, and the respondent's awareness of local AIDS control program efforts. The questionnaire addressed the research questions by including questions on HIV prevalence trends in Uganda and Fort Portal since 1991, and explanations for these trends. Questions on proxy measures of HIV prevalence, such as stigma and AIDS-related deaths, and observed changes in sexual behaviour were also included. Other questions related to awareness of and agreement with the Ugandan HIV/AIDS "Success Story", and satisfaction with how HIV/AIDS outcomes have been communicated to the public.

Questionnaires were translated into the local language, Rutooro, and were tested for linguistic reliability by being translated back into English by a different translator. Both English versions were compared and any differences were corrected by consensus with all translators present. The interviews lasted on average between 40 - 60 min.

### Selection of participants

In this study, we used the cluster sampling method as developed and applied by the World Health Organization for the evaluation of the Extended Program of Immunization (EPI) (Hoshaw-Woodard, 2001). Thirty six clusters (villages) were randomly selected from a list of all 93 villages in the study area. Households in each village included in the study were selected using the same method: A central point in each village, usually the market, was chosen as a starting point from which a direction was randomly selected, and the seven nearest households in this direction were visited for the survey. In each selected household, one participant was randomly selected of all persons over 18 years available on the day of the survey. The total number of study participants included was 252.

### Data collection and analysis

The questionnaire was administered during a face-to-face interview in the homes of respondents. Interviews were conducted in a private and comfortable place chosen by the respondent. Qualified interviewers who had undergone a two-day training session on questionnaire content and interviewing technique conducted the in-

**Table 1.** Demographic information on the study participants.

Variable		Total		Male		Female	
		N = 252	%	N = 101	%	N = 151	%
Subcounty	Eastern Zone	78	31.0	31	30.7	47	31.1
	Southern Zone	112	44.4	41	40.6	71	47.0
	Western Zone	62	24.6	29	28.7	33	21.9
Respondent's house	Semi-permanent	152	60.3	65	64.4	87	57.6
	Permanent	99	39.3	35	34.7	64	42.4
	Temporary	1	0.4	1	1.0		
Respondent Role	Head of household	84	33.5	56	55.4	28	18.7
	Spouse	83	33.1	3	3.0	80	53.3
	Son/daughter	54	21.5	27	26.7	27	18.0
	Relative	22	8.8	11	10.9	11	7.3
	Employee	6	2.4	2	2.0	4	2.7
	Friend	1	0.4	1	1.0		
	Other	1	0.4	1	1.0		
	Unknown/missing	1					
Age in years	18-25	98	38.9	37	36.6	61	40.4
	26-35	74	29.4	35	34.7	39	25.8
	36-45	27	10.7	9	8.9	18	11.9
	45+	53	21.0	20	19.8	33	21.9
Sex	Male	101	40.1	-	-	-	-
	Female	151	59.9	-	-	-	-
Religion	Catholic	117	46.4	52	51.5	65	43.0
	Protestant	77	30.6	26	25.7	51	33.8
	Muslim	33	13.1	16	15.8	17	11.3
	Pentecostal	13	5.2	1	1.0	12	7.9
	Seventh Day Adventist	7	2.8	3	3.0	4	2.6
	Cults	4	1.6	2	2.0	2	1.3
	Other	1	0.4	1	1.0		
Occupation	Self-employed	95	37.8	55	55.0	40	26.5
	Student	34	13.5	18	18.0	16	10.6
	Peasant	32	12.7	8	8.0	24	15.9
	Unemployed	21	8.4	1	1.0	20	13.2
	Housewife	19	7.6			19	12.6
	Professional	14	5.6	6	6.0	8	5.3
	Farmer	12	4.8	3	3.0	9	6.0
	Retired	11	4.4	4	4.0	7	4.6
	Other	9	3.6	4	4.0	5	3.3
	Businessman/woman	4	1.6	1	1.0	3	2.0
	Unknown/missing	1		1			
Monthly Income (ugsh)	Seasonal	48	19.9	10	10.3	38	26.4
	< 100 000	138	57.3	61	62.9	77	53.5
	100 000 - 200 000	37	15.4	17	17.5	20	13.9
	200 000 – 300 000	12	5.0	4	4.1	8	5.6
	> 300 000	6	2.5	5	5.2	1	0.7
	Unknown/missing	11		4		7	

Table 1. Contd.

Marital status	Single	111	44.6	64	64.0	47	31.5
	Married	95	38.2	32	32.0	63	42.3
	Widowed	28	11.2	3	3.0	25	16.8
	Divorced	15	6.0	1	1.0	14	9.4
	Unknown/missing	3		1		2	
Education	No education	27	10.7	7	6.9	20	13.2
	Lower primary	28	11.1	11	10.9	17	11.3
	Upper primary	82	32.5	32	31.7	50	33.1
	O-levels	77	30.6	31	30.7	46	30.5
	Technical	4	1.6	4	4.0		
	A-levels	8	3.2	5	5.0	3	2.0
	Tertiary institutions	24	9.5	10	9.9	14	9.3
	Other	2	0.8	1	1.0	1	0.7

interviews in the local language. Completed questionnaires were checked for accuracy and completeness every day and then entered into Microsoft Access. A data codebook was created in Microsoft Word to assist with the transformation of data from the questionnaire. Data was entered into the computer using SPSS 14.0. Statistical analysis included descriptive analysis and frequency distributions. Bivariate analysis was performed to evaluate statistical significance between the main variables and different groups, using the chi square test.

#### Ethics approval

This study was cleared by the Ethics Review Board (Panel B) of the University of Alberta. Approval in Uganda was obtained from the Uganda National Council of Science and Technology and from the Kabarole District Health Officer (DHO) prior to commencing data collection. Informed consent was obtained from all study participants. For this purpose, a written information letter outlining the purposes and implications of the study and clarifying the voluntary nature of their participation was provided or read, and agreed to either by signing or thumb printing the consent form prior to commencing the interview. No names of interviewees were recorded.

## RESULTS

Of our participants, 101 (40.1%) were male and 151 (59.9%) were female. As many males were working during the day and were not available, the final sample included more females than males. The final female : male ratio of study participants was 60:40. Respondents were evenly distributed over Fort Portal Municipality, which is divided into three main geographical zones. Seventy-eight respondents (31% of the sample) resided in the eastern zone, 112 (44.4%) in the more populous southern zone, and 62 (24.6%) in the western zone.

Respondents ranged in age from 18 - 89 years, with a mean age of 33.3 years. The sample was relatively young, with 38.9% belonging to the 18 - 25 year age group. One hundred eleven (44.6%) respondents were single, 95 (38.3%) were married, 28 (11.2%) were widow-

ed and 15 (6.0%) were divorced. In general, the sample reflected very well the socio-economic profile of the study area, except that more women than men were recruited. Table 1 shows the demographic details.

#### Awareness of the HIV/AIDS control program in Kabarole district

When asked if they were aware of the AIDS control program in Kabarole District, 94.0% replied yes, while the remaining 6.0% were not aware. The most widely mentioned program components were AIDS education and awareness programs, volunteer testing and counseling (VCT), prevention of mother-to-child transmission services (PMTCT), and antiretroviral (ARV) treatment. When asked how they had learned about the programs, the most common response was through radio and television, followed by health workers at hospitals and clinics. Other frequently cited information sources were newspapers and magazines.

#### Awareness of HIV prevalence trends in Uganda

Respondents were asked to comment on whether HIV prevalence in Uganda had increased, decreased or stayed the same since 1990. Nearly half the sample (48.4%) stated that HIV infection had increased in Uganda since the early 1990s while 44.8% said it had decreased, and 3.6 % said that HIV infection levels had stayed the same. Women were more likely than men to say that HIV had increased (53.0 vs 41.6%,  $p = 0.029$ ). Likelihood of saying that HIV prevalence had decreased was associated with higher education, though not statistically significant ( $p = 0.206$ ).

To find out which channels of information were most commonly used in communicating HIV prevalence trends to the public respondents were asked how they had found

out that HIV was increasing/decreasing. Personal observation (usually defined as seeing people sick with or dying of HIV/AIDS in the immediate area) was the most often mentioned source of information on HIV prevalence trends, reported by 62.3% participants. Once again, radio and television were frequently mentioned sources (54.4%), as were health workers at hospitals and clinics (15.1%). Print media such as newspapers and magazines were mentioned less frequently.

### **Explanations for declining HIV prevalence in Kabarole/Uganda**

Survey respondents were asked to explain why they thought HIV was increasing or decreasing. Of those who said that Uganda's HIV trend had increased or stayed the same, the most frequent explanation was lack of sexual behaviour change ("people are not changing", infidelity, multiple partners, rape, etc 93.4% of respondents). Other frequent explanations included people ignoring AIDS control messages (48.4%), lack of condom use (28.7%), and bad lifestyle choices such as drinking and drug use (20.5%). Sugar Daddies - men who entice young women into sexual relationships through promises of money or gifts - were cited by 8.2% of participants.

Of the 113 respondents who stated that Uganda's HIV trend had decreased, the decrease was most frequently attributed to AIDS education and awareness (75.2%). Respondents also frequently cited behaviour changes related to Uganda's ABC strategy (condom use 38.1%; faithfulness 27.4% and abstinence 23.0%). Thirty-six (31.9%) of those answering that HIV had decreased cited the availability and use of ARV drugs as an explanation, while 22.1% cited use of voluntary counselling and testing (VCT) services. When respondents were asked to comment on HIV prevalence trends in Fort Portal (their local township) since 1991 and to give their explanations for these trends, respondents' answers did not significantly differ from their perceptions of the national-level trends, that is, approximately half said that the HIV prevalence had declined and the other half said that HIV had increased. Regarding stigma against people with HIV/AIDS, nearly half the sample said that stigma had eased since the early 1990s.

### **Influence of behavior change on HIV prevalence trends**

One hundred and six (106) respondents commented on the impact of behavior change on HIV trends, and changes relating to the "ABC" strategy dominated their responses. Sixty six percent said that behaviour changes had helped to decrease HIV infection in their area. More males than females stated that sexual behaviour change had occurred in their villages. However, it was only borderline statistically different ( $p = 0.100$ ). Respondents were asked to elaborate by listing the types of behaviour

changes they were seeing. The most common change cited was faithfulness (59.4%) followed by increased condom use (46.2%) and abstinence (41.5%). Interestingly, males were more likely to cite "ABC"-related behaviour changes than females, though it was not a statistically significant difference ( $p = 0.197$ ). Increased levels of HIV/AIDS education and awareness, although not a direct behaviour change, were also mentioned by 25.5% of respondents (Figure 1).

### **The "Ugandan Success Story"**

Sixty five percent of respondents said they had heard about the "Ugandan Success Story" before, while 34.9% had not. When comparing male and female respondents, it was noted that females were less likely to have heard about the success story than males ( $p = 0.126$ ). Out of the majority of the respondents who had heard of the success story, 68.3% agreed with it. The main reasons respondents said they agreed was because of seeing less deaths from HIV/AIDS in their immediate area, availability and low cost of ARV drugs and the increased HIV education and awareness programs that formed part of the national and district AIDS Control Program. Of the respondents who disagreed with the success story, the main reason given was that the number of deaths from HIV/AIDS that they observed in their immediate area had stayed the same or had increased.

### **Preferred methods of communication**

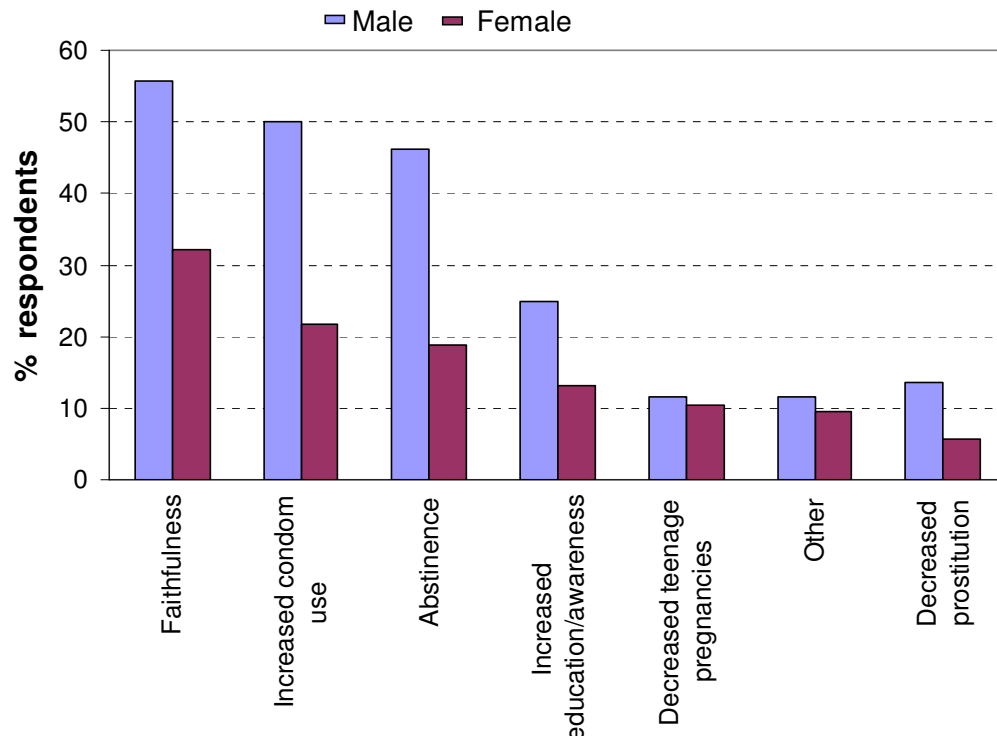
When respondents were asked to suggest methods that the government could use to communicate information on HIV prevalence trends to the public, previously preferred means of communication were repeated: radio and television were mentioned by 75.8%. Grassroots-level strategies for information dissemination were also popular. These included household visits, than followed by community visits by leaders, village peer educators and drama groups. More formal channels such as schools and teachers, churches and mosques were less often recommended.

## **DISCUSSION**

This study is one of few attempts to capture public knowledge and opinions on HIV prevalence trends and their causes in order to try to supplement ongoing (and frequently conflicting) scientific and professional discussions of Uganda's success in HIV/AIDS control.

This study seemed especially necessary as we did not find any previously published information from Uganda on the public's knowledge and interpretation of Ugandan HIV prevalence trends.

It was encouraging to learn that almost all participants interviewed knew about the HIV/AIDS control program in



**Figure 1.** Reported behaviour changes by males and females responsible for a declining HIV prevalence (n = 106) (statistically significant differences in responses to faithfulness, decreased prostitutions at  $p < 0.05$  level, to condom use and abstinence at  $p < 0.001$  level, others not statistically significant).

the district and its efforts to curb the spread of HIV. Although a good proportion of respondents stated that they believed that HIV prevalence has declined in both Uganda and Fort Portal (44.8 and 41.4% respectively), we would have expected this proportion to have been higher, because of the strong efforts of the government and the churches to educate the public.

The most important finding that justified the study aim of capturing public perceptions was that those respondents who believed HIV prevalence had declined also rated positive sexual behavior changes as one of the major explanations for this decline. This corresponds very well with two of our previous studies from the same area: the first found the declining HIV prevalence to be a consequence of increased safe sex behaviors (Kilian et al., 1999); and the second, examining specific changes in sexual behavior, found that changes consist mostly of an increase in condom use, and to a lesser extent, of increased abstinence and a reduction in number of sexual partners (Kilian et al., 2007). The results from this public opinion survey are quite similar: faithfulness and condom use were mentioned more often as a behavior change mechanism to explain the declining HIV prevalence compared to abstinence which was stated as a less likely cause for the HIV prevalence decline. In addition, most respondents stated that “ABC” as a comprehensive component (and not individual components of

it) was the most likely explanation for the declining HIV prevalence. The multi-method approach to HIV prevention programs has been reflected by other authors who maintain that the decline in HIV prevalence in Uganda is best explained through a combination of several interventions as it was implemented in Uganda using the “ABC” approach (Singh et al., 2003; Cohen, 2004; Wilson, 2004). The public perceptions presented in this study agree with this research and also reinforce that abstinence alone may be a less important factor in the prevalence decline. Public perception thus disagrees with the currently advocated “abstinence only” approach by some to halting the spread of HIV (Blum, 2004).

The limited public knowledge of the bigger picture, that the HIV/AIDS trends in Uganda has declined over time, is perhaps best explained by the focus of many educational messages on individual responsibilities and safe sexual behavior. During our study several health officials and lay persons were of the opinion that it would be too dangerous to let the public know the true situation of a declining HIV prevalence. They argued that this could lead to complacency and a relaxation of behaviors advocated through the programs. On the contrary, we argue that the full knowledge of the public on advancements in the fight to halt the spread of HIV will reinforce and sustain safe sexual behavior changes rather than lead to complacency and relaxed safe sex practices.

## Limitations

Our study has the following limitations: 1) It was done in an urban setting, where people are generally more educated and more aware of HIV/AIDS compared to rural populations; 2) We could not rely on a developed and tested interview guide, as it was not available. This was dealt with by careful formulation of the questions for ease of understanding, extensive pre-testing of the questionnaire and employing well-trained interviewers to minimize interview bias; 3) we cannot exclude response bias of respondents in order to please the interviewers.

## Conclusions

Ongoing controversial discussion by some professionals and scientists as to what constitutes the "Ugandan Success Story" reinforces the need to learn more about all the ingredients for successfully controlling HIV/AIDS. Our data from this public opinion poll supports what informed professionals and many published studies have already substantiated: that the declining HIV prevalence in Uganda is best explained by multiple changes in sexual behaviors and not by abstinence only. Public perceptions of these changes in the HIV/AIDS epidemic are an important contribution to the overall perspective and interpretation of the "Ugandan Success Story" because it eliminates some of the controversy around ingredients for success. The lesson we have learned is that public opinion polls should be done more often in developing countries because it is a meaningful perspective and adds balance for informing government policy, for scientific discussion, and for rallying public support.

## ACKNOWLEDGEMENTS

We thank Jean Kipp for her comments on the first draft. We are indebted to the participants who agreed to participate in this study and spent their valuable time to be interviewed. The study was funded by a grant from the Fund for Support of International Development Activities (FSIDA) of the University of Alberta, Edmonton, Canada and the Canadian Institutes of Health Research (CIHR).

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