

Processes and Outcomes of HIV Serostatus Disclosure to Sexual Partners among People Living with HIV in Uganda

Rachel King · David Katuntu · Julie Lifshay · Laura Packel · Richard Batamwita · Sylvia Nakayiwa · Betty Abang · Frances Babirye · Pille Lindkvist · Eva Johansson · Jonathan Mermin · Rebecca Bunnell

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Abstract Disclosure of HIV serostatus to sexual partners supports risk reduction and facilitates access to prevention and care services for people living with HIV/AIDS. To assess health and social predictors of disclosure as well as to explore and describe the process, experiences and outcomes related to disclosure of HIV-infected men and women in Eastern Uganda, we conducted a study among HIV-infected men and women who were clients of The AIDS Support Organization (TASO) in Jinja, Uganda. We enrolled TASO clients in a cross-sectional study on transmission risk behavior. Demographic and behavioral data and CD4 cell count measurements were collected. Among 1,092 participants, 42% were currently sexually active and 69% had disclosed their HIV serostatus to their most recent sexual partner. Multivariate logistic regression analysis showed that disclosure of HIV-status was associated with

being married, having attended TASO for more than 2 years, increased condom use, and knowledge of partner's serostatus. From these clients, 45 men and women were purposefully selected and interviewed in-depth on disclosure issues. Positive outcomes included risk reduction behavior, partner testing, increased care-seeking behavior, anxiety relief, increased sexual communication, and motivation to plan for the future.

Keywords HIV · Uganda · Counseling and testing · Disclosure · Prevention with positives · Sexual behavior

Introduction

A person's ability to effectively prevent HIV transmission and acquisition is supported by knowledge of personal and partner HIV serostatus and the protective behaviors and practices associated with that knowledge. Counseling and testing for HIV combined with disclosure of HIV serostatus to sexual partners and others can enable persons living with HIV/AIDS (PLWHA) to seek appropriate care and treatment and can allow both PLWHA and uninfected persons to make informed choices about their sexual behavior (WHO 2003).

Both in the industrialized and the developing world, disclosure to sexual partners is recommended during post-test counseling since it supports risk reduction behaviors and facilitates access to prevention, care and treatment services for PLWHA, their partner(s) or infant(s) (Gielen et al. 2000; Kalichman and Nachimson 1999). Disclosure of HIV serostatus benefits the individual disclosing by reduction of anxiety and depression (Armistead et al. 1998; Kalichman et al. 2003) and leads to increased medical and social support and preventive behaviors (Medley et al. 2004).

The findings and conclusions in this report are those of the author and do not necessarily represent the views of the Centers for Disease Control and Prevention.

R. King · D. Katuntu · R. Batamwita · S. Nakayiwa · B. Abang · J. Mermin · R. Bunnell
Global AIDS Program, CDC-Uganda, Kampala, Uganda

R. King (✉)
Uganda Virus Research Institute, CDC-Uganda, P.O. Box 49,
Entebbe, Uganda
e-mail: rking@prefa.or.ug

J. Lifshay · L. Packel
University of California, Berkeley, Berkeley, CA, USA

F. Babirye
The AIDS Support Organization (TASO), Kampala, Uganda

P. Lindkvist · E. Johansson
Karolinska Institute, Stockholm, Sweden

Rates of serostatus disclosure by HIV-infected individuals to their sexual partners are similar worldwide, with an average for women of 71% (range 42–100%) in the US and Europe (Armistead et al. 1998; Hays et al. 2003; Simoni et al. 1995; WHO 2003), and 52% (range 16–86%) in Africa (WHO 2003). Within countries, rates and patterns of disclosure vary by ethnicity, gender, and situation, with the lowest rates reported among women attending antenatal care (WHO 2003).

In the developing world, especially among pregnant women, barriers to disclosure include fear of blame, abandonment, rejection (Pool et al. 2001), physical abuse (Temmerman et al. 1995), disgrace to self and family (Chandra et al. 2003), stigma and discrimination (Kilewo et al. 2001), accusations of infidelity, and loss of economic support (Medley et al. 2004).

Factors that motivate disclosure to partners, family, and friends in the less industrialized world include length of time since diagnosis, severity of illness, a sense of ethical responsibility to partners, social support from friends and family, minimizing stress associated with non-disclosure, and disclosure as a way to facilitate HIV preventive behavior (WHO 2003). In addition, factors predictive of disclosure include younger age (Farquhar 2000), fewer sexual partners, and personally knowing someone with AIDS (Antelman et al. 2001).

Though an emotionally stressful event, disclosure leads to primarily positive social outcomes (Siegel et al. 2005; Kilewo et al. 2001). In Tanzania, disclosure was associated with significantly higher rates of positive than negative outcomes (Maman et al. 2003). Common positive outcomes included increased social and medical support, acceptance and kindness, decreased anxiety and strengthening of relationships (WHO 2003). In a comprehensive review conducted by WHO globally, rates of reported negative outcomes affected a small proportion (less than 5%) of those who disclosed (WHO 2003). When present, these included blame, abandonment, anger, violence, stigma and depression (WHO 2003). Violence was rare, generally associated with a history of violence in relationships (WHO 2003), and was more common among HIV-discordant couples (Maman et al. 2003).

Three qualitative studies describe supportive as well as violent reactions to HIV-positive serostatus disclosure among a primarily African-American female population in the US (Gielen et al. 1997), the role of disclosure in coping with HIV among 40 gay and bi-sexual men in the UK (Holt et al. 1998) and women's barriers to HIV serostatus disclosure among VCT attendees in Tanzania (Maman et al. 2001). Thus, there is limited in-depth information regarding the processes and experiences of HIV serostatus disclosure among PLWHAs in Africa as well as the

behavioral constructs that may inhibit or facilitate disclosure in this population. The purpose of this paper is to provide both an assessment of health and social predictors of disclosure based on behavioral constructs principally stemming from the health belief model and the theory of reasoned action, as well as to describe experiences and outcomes related to disclosure among HIV-infected men and women in Eastern Uganda.

Methods

Setting

Between October 2003 and August 2004, HIV-infected TASO clients were recruited at the center in Jinja, a town in Eastern Uganda and at two additional outreach sites. At the time of the study, the TASO Jinja center provided counseling, social support and medical care, but not anti-retroviral therapy (ART).

Sampling and Recruitment

Participants were recruited during routine TASO clinic visits. After a group education session introducing the study to clients in the waiting area, interested clients were evaluated regarding eligibility criteria; these included being ≥ 18 years of age and healthy enough to participate in an interview and blood draw. Potential participants were selected randomly and provided written informed consent for participation. Random selection was conducted by field officers who prepared lottery papers for the corresponding number of clients who had registered that day. All potential participants meeting the eligibility criteria had HIV infection confirmed through sequential serologic testing using Abbott Determine HIV-1/2 (Abbott Diagnostics, Illinois, USA) as the initial screening test and HemaStrip HIV-1/2 (Chembio Diagnostics Systems, New York, USA) as the confirmatory test. The sample size was calculated based on the main outcome (difference of proportion reporting condom use at last sex between disclosed and not), a power of .80, and alpha of .05 to detect a difference of 20%. A total of 480 clients per gender was needed to determine this difference, considering a minimum response rate of 85% and an estimated proportion of TASO clients being male of 30%. Thus, a total of 1,092 clients was selected, from whom a subset of 23 men and 24 women were purposefully selected to participate in in-depth interviews. Interview selection was based on the following criteria: gender, disclosure (equally distributed between disclosed and not disclosed), and reported recent sexual activity (categorized into 15 risky sex; 17 safe sex; and 13 abstaining).

Measures

Measures used in the quantitative components of this study were defined as follows:

Risky sex was defined as inconsistent or no condom use with a partner of HIV-negative or unknown status while *safe sex* was defined as always using a condom or having sex with a concordant HIV-positive partner.

Discuss sexual issues with partners was defined as client reporting having discussed their sexual life with their partner.

Knowledge of partner status was defined as clients' response to the question, 'what is your partner's HIV serostatus'?

TASO clients received counselling, treatment, nutritional and orphan support as well as a basic care package that includes a safe water vessel, insecticide treated bed nets, condoms and educational materials about positive living.

Years spent as a TASO client was calculated by subtracting the interview date from the clients' TASO registration date.

All participants in this study provided written informed consent. The study was approved by the Institutional Review Boards of the Uganda Virus Research Institute, the University of California, Berkeley, USA and the Centers for Disease Control and Prevention, USA.

Quantitative Data Collection, Management and Analysis

A quantitative questionnaire focusing on sexual risk behavior, voluntary counseling and testing (VCT) and prevention of mother-to-child transmission (PMTCT) was administered to 1,092 participants (488 men and 604 women). Data were double-entered using Epi-Info (version 2000, Atlanta, Georgia, USA) and analyzed in SAS version 9.1 (SAS Institute, Cary, North Carolina, USA). HIV serostatus disclosure patterns (whom disclosed to, time between HIV test and disclosure, difficulty disclosing, and reason for disclosing) were assessed separately for men and women. We developed a multivariate logistic regression model to assess associations between HIV disclosure by participants to their most recent sexual partner and socio-demographics, sexual behavior, condom use, health characteristics, knowledge of partner's HIV status and years enrolled at TASO. For this analysis, we excluded 308 individuals who reported last having sex on a date prior to receiving their HIV test result.

Qualitative Data Collection and Analysis

Between April and June 2004, five trained Ugandan interviewers conducted 45 individual in-depth semi-structured interviews with clients who had a sexual partner since the time of their first positive HIV test. Interviews were conducted in the clients' choice of local languages or English at either a TASO Jinja clinic site or in the respondent's home. After obtaining client consent, interviewers tape-recorded the 2–3 hour sessions. Interview topics included barriers and motivating factors for disclosure; benefits and effects of not disclosing; reasons to disclose; techniques, methods and experiences in disclosing; and intentions and norms around disclosure.

In-depth interviews were transcribed, translated into English, and coded by an analysis team consisting of two interviewers and two social scientists. Standard guidelines were used for thematic coding as the primary analytic strategy (Boyatzis 1998). After reading two transcripts, the analysis team members collaboratively developed a codebook of themes around the main interview topics. A second sample of two transcripts was then reviewed to add additional topic areas and themes that emerged. This process was repeated until a sample of 12 transcripts had been reviewed and the codebook had reached a stage where no new themes or topic areas emerged from reading unique transcripts. To ensure inter-rater consistency, the analysis team compared their individual coding of the transcripts. All transcripts were then coded using the final version of the codebook and merged using NVivo software before themes were summarized across respondents (version 2.0, QSR International Pty. Ltd, Victoria, Australia).

Findings

Quantitative

Among 1,092 study participants the median age was 37 for women and 40 for men. Most participants were widowed, separated or divorced (55%), had completed at least primary school (51%) and had a salaried job (29%), a small business (25%), or worked in subsistence farming (27%). Of all respondents, 42% reported being sexually active and of those, 69% had disclosed their HIV-positive status to their most recent sexual partner. Eighty percent of respondents had discussed sexual issues with their partners and 39% had two or more relatives who had died of AIDS (Table 1). Men were most likely to disclose their HIV status to their sexual partners (27%) and brothers (21%), and women to their sisters (21%). Eighty-three percent of respondents disclosed (to anybody) on the same day they received their test results with no significant difference

Table 1 Socio-demographic characteristics by gender; quantitative and qualitative samples

Socio-demographic characteristic	Total <i>N</i> (%) <i>N</i> = 1092	Male (%) <i>N</i> = 488	Female (%) <i>N</i> = 604	Qualitative <i>N</i> (%) <i>N</i> = 45
<i>Age (Years)</i>				
≤30	187 (17)	(12)	(22)	10 (22)
31–40	518 (48)	(47)	(47)	20 (45)
41–49	296 (27)	(30)	(25)	11 (24)
50+	90 (8)	(11)	(6)	4 (9)
<i>Education</i>				
None	118 (11)	(8)	(14)	3 (6)
Primary	558 (51)	(46)	(55)	28 (62)
Post-primary	416 (38)	(46)	(31)	14 (32)
<i>Religion</i>				
Catholic	262 (24)	(26)	(22)	14 (31)
Protestant	433 (40)	(41)	(39)	21 (47)
Moslem	203 (18)	(18)	(19)	7 (15)
Other	193 (18)	(15)	(20)	3 (7)
<i>Marital status</i>				
Single	23 (2)	(2)	(2)	1 (2)
Married/co-habiting	474 (43)	(69)	(23)	28 (62)
Widowed/separated/divorced	595 (55)	(29)	(75)	16 (36)
<i>Occupation</i>				
Subsistence farming	296 (27)	(22)	(31)	9 (20)
Wage employment/small business	276 (25)	(27)	(24)	15 (33)
Salaried employment/commercial/farmer/businessman	319 (29)	(35)	(25)	16 (36)
Unemployed	137 (13)	(9)	(16)	5 (11)
Other	63 (6)	(7)	(4)	0 (0)
<i>Number of living children</i>				
0–1	159 (15)	(13)	(16)	3 (7)
2–4	500 (46)	(41)	(50)	22 (52)
5+	431 (39)	(46)	(34)	17 (41)
<i>CD4 count (per mm³)</i>				
≤200	610 (56)	(61)	(52)	19 (42)
>200	482 (44)	(39)	(48)	26 (58)
<i>Years attending TASO</i>				
Less than 6 months	319 (30)	(46)	(16)	11 (24)
6 months–2 years	405 (37)	(31)	(43)	22 (49)
More than 2 years	360 (33)	(23)	(41)	12 (27)
<i>Number of relatives that have died of AIDS</i>				
0	331 (30)	(43)	(21)	20 (45)
1	337 (31)	(29)	(32)	11 (24)
2+	423 (39)	(28)	(47)	14 (31)
<i>Type of most recent sexual partner</i>				
Spouse	725 (66)	(78)	(58)	30 (67)
Steady	223 (21)	(10)	(29)	12 (27)
Casual	141 (13)	(12)	(13)	3 (6)
<i>Discussed sexual issues with most recent sexual partner</i>				
Yes	870 (80)	(85)	(76)	39 (87)

Table 1 continued

Socio-demographic characteristic	Total <i>N</i> (%) <i>N</i> = 1092	Male (%) <i>N</i> = 488	Female (%) <i>N</i> = 604	Qualitative <i>N</i> (%) <i>N</i> = 45
<i>Condom use</i>				
Always	316 (29)	(34)	(25)	16 (36)
Sometimes	263 (24)	(25)	(24)	10 (22)
Never	509 (47)	(41)	(51)	19 (42)
<i>Knowledge of partner's HIV status</i>				
Positive (tested)	266 (24)	(27)	(23)	8 (18)
Negative (tested)	64 (6)	(10)	(3)	4 (9)
Don't know	758 (70)	(63)	(74)	33 (73)
<i>Sexually active in past 3 months</i>				
Yes	455 (42)	(52)	(34)	33 (73)

between genders. Eighty-seven percent stated that it was not difficult to disclose their status, with no difference between genders. The most frequently mentioned reason for disclosing among both men (21%) and women (27%) was access to medical or home care (Table 2).

Multivariate logistic regression showed that the odds of disclosure among clients who were married or co-habiting were 11 times higher (95% CI 1.98–60.39) and those who were widowed, separated or divorced were three times higher (95% CI 0.50–15.18) than those who were single (Table 3). Length of time as a TASO client was independently associated with disclosure (6 months to 2 years: adjusted OR 1.47, 95% CI 0.94–2.31; more than 2 years: adjusted OR 2.49, 95% CI 1.45–4.27). The odds of disclosure were two times higher among clients who 'sometimes' or 'always' used condoms compared to those who 'never' used them. In addition disclosure was independently associated with knowledge of partner status; especially for clients who knew that their partner was HIV infected (adjusted OR 10.93, 95% CI 6.39–18.70) (Table 3). Neither having a household member who had died of AIDS nor, CD4 counts or WHO clinical stage was associated with disclosure.

Qualitative Findings

Process and Techniques Around Disclosure

Among the 45 participants selected for in-depth interviews 33 (73%) had disclosed their HIV serostatus (17 women and 16 men). Demographic and health characteristics of this sub-sample are presented in Table 1. In Uganda as elsewhere, disclosure to sexual partner has been promoted as a prevention strategy focused on partner notification to enable sexual partners to access testing and care services and the HIV infected person to confront

stigma and discrimination. This model is founded on a concept of direct face-to-face communication in which HIV-infected individuals discuss their results directly with their sexual partner. We found that among our study participants, communication in general and disclosure in particular can be a complex process and can come in diverse forms such as stories, parables, or other indirect routes. As shown in Fig. 1, disclosure techniques included; direct (55%), indirect (27%), and assisted (18%) methods.

Direct Face-to-face Discussion

About half of the qualitative respondents disclosed directly and did so as a result of worsening health though CD4 counts and clinical stage were not associated with disclosure in the quantitative study. Symptoms of herpes zoster, TB, pneumonia and other infections prompted respondents to test and disclose. One of the respondents commented that when he fell ill, one of his wives suggested he go to test. After receiving his results he disclosed directly to four wives; "We were having tea when I told them that there was a problem in the home—that I had tested HIV positive" (51-year-old man).

Indirect Disclosure

In order to initiate discussion around HIV serostatus, respondents mentioned various types of indirect methods. One method included narration about other people such as neighbors or influential people in the community who had already fallen sick. Another consisted of respondents' account of their own potentially HIV-associated conditions, which are not stigmatized in Uganda. Several respondents felt that relating the story

Table 2 Description of disclosure characteristics for HIV-infected men and women in Uganda

Disclosure characteristic	All (<i>N</i> = 1,092) <i>N</i> (%)	Men (<i>N</i> = 488) <i>N</i> (%)	Women (<i>N</i> = 604) <i>N</i> (%)	χ^2
<i>First person disclosed to</i>	<i>n</i> = 1,052	<i>n</i> = 459	<i>n</i> = 593	81.5289*
Spouse/sexual partner	210 (20)	125 (27)	85 (14)	
Mother	155 (15)	43 (9)	112 (19)	
Father	37 (4)	24 (5)	13 (2)	
Brother	169 (16)	96 (21)	73 (12)	
Sister	178 (17)	56 (12)	122 (21)	
Biological child	62 (6)	14 (3)	48 (8)	
Other relative	86 (8)	30 (7)	56 (10)	
Friend/neighbor	114 (11)	53 (12)	61 (10)	
Religious leader	16 (1)	8 (2)	8 (1)	
Other	25 (2)	10 (2)	15 (3)	
<i>Main reason disclosed</i>	<i>n</i> = 1,052	<i>n</i> = 459	<i>n</i> = 593	17.5692*
Emotional/spiritual support	154 (15)	69 (15)	85 (14)	
Financial support	84 (8)	42 (9)	42 (7)	
Medical/home care	255 (24)	94 (21)	161 (27)	
S/he knew client was sick	154 (15)	66 (14)	88 (15)	
So family would know cause of death	180 (17)	82 (18)	98 (17)	
Encourage others/partner to test	61 (5)	37 (8)	24 (4)	
Both tested on same day	62 (6)	32 (7)	30 (5)	
Other	102 (10)	37 (8)	65 (11)	
<i>Disclosed on day tested positive</i>	<i>n</i> = 1,048	<i>n</i> = 459	<i>n</i> = 589	0.0050
Yes	870 (83)	381 (83)	489 (83)	
<i>Difficult to disclose</i>	<i>n</i> = 1,005	<i>n</i> = 460	<i>n</i> = 593	0.0028
Yes	138 (13)	60 (13)	78 (13)	
No	867 (87)	400 (87)	515 (87)	

* $P \leq 0.05$ by χ^2 for difference between groups: men and women

of a third person normalized issues around HIV and prepared the listener for the difficult news: “We were talking and there was a person who came by who had AIDS. Then I said [to my husband], ‘You saw that sick person? I am also going to die like that.’ He asked me what I meant. I explained that I went to Mayuge and tested; I was told that I have HIV” (49-year-old woman).

Placing condoms, HIV-related medications, and referral forms in a place where a partner could see them or showing them to a sexual partner were other methods that both male and female respondents used to initiate and or confirm HIV serostatus disclosure. For most respondents this method served as an entry point into the discussion of HIV results, whereas some of them used this method as the actual disclosure itself. “So that evening when he came, we just conversed and then I got out my book plus the card [from health center]. I showed them to him” (49-year-old woman). Some clients waited for their partner to ask about the medicine they had purposefully left on a table and used the opportunity to disclose.

Assisted Disclosure

While dialogue around assisted disclosure was sometimes described as a hypothetical discussion most cases related to lived experience. Some respondents used a professional or a friend to either prepare their sexual partners for disclosure or to actually disclose to them. This method was perceived as particularly useful for individuals who were afraid of the reactions of their partners or were less confident about their communication skills.

At first I didn't tell her, because I knew that if I told her, she would get very worried. You never know, she might even decide to separate with me. So I sent my friend to her. He talked to her slowly, slowly. ‘You know that on and off malaria your husband has?’ he said. ‘I will take him for an HIV test’... Now the day my friend escorted me for the HIV test, ... I tested positive ... he didn't tell her. Two weeks passed, then he told her that I had tested positive for HIV (34 year-old man).

Table 3 Association between demographic and health characteristics and HIV sero-status disclosure among HIV-infected men and women in Jinja, Uganda (N = 784)

Socio-demographic characteristic	N (%)	Disclosure prevalence (overall = 64%)	Unadjusted OR [†] (95% CI)	Adjusted OR [†] (95% CI)
<i>Sex</i>				
Male	416 (53)	267 (64)	1.00 (ref)	1.00 (ref)
Female	368 (47)	231 (63)	0.93 (0.70, 1.25)	1.26 (0.81, 1.97)
<i>Age (Years)</i>				
≤30	127 (16)	77 (55)	1.00 (ref)	1.00 (ref)
31–40	397 (51)	253 (65)	1.48 (0.996, 2.19)*	1.08 (0.65, 1.81)
41–50	201 (26)	134 (68)	1.71 (1.09, 2.68)*	1.19 (0.65, 2.16)
51+	59 (7)	32 (62)	1.29 (0.67, 2.47)	1.17 (0.50, 2.72)
<i>Education</i>				
None	68 (9)	40 (60)	1.00 (ref)	1.00 (ref)
Primary	407 (52)	263 (65)	1.25 (0.74, 2.12)	1.36 (0.69, 2.68)
Post-primary	309 (39)	195 (63)	1.16 (0.67, 1.98)	1.11 (0.55, 2.25)
<i>Religion</i>				
Catholic	193 (24)	127 (66)	1.00 (ref)	1.00 (ref)
Protestant	312 (40)	184 (59)	0.73 (0.50, 1.06)	0.78 (0.48, 1.26)
Moslem	154 (20)	100 (65)	0.93 (0.60, 1.46)	0.87 (0.50, 1.51)
Other	125 (16)	87 (70)	1.15 (0.71, 1.87)	1.02 (0.56, 1.87)
<i>Marital status</i>				
Single	14 (2)	3 (21)	1.00 (ref)	1.00 (ref)
Married/co-habiting	474 (60)	345 (73)	9.96 (2.73, 36.26)*	10.94 (1.98, 60.39)*
Widowed/separated/divorced	296 (38)	150 (51)	3.79 (1.04, 13.87)*	2.77 (0.50, 15.18)
<i>Occupation</i>				
Subsistence farming	195 (25)	137 (71)	1.00 (ref)	1.00 (ref)
Wage employment/small business	207 (26)	126 (61)	0.66 (0.44, 1.01)*	0.62 (0.37, 1.04)
Salaried employment/commercial farmers/businessmen	254 (33)	148 (58)	0.58 (0.39, 0.86)*	0.48 (0.29, 0.79)*
Unemployed	78 (10)	52 (67)	0.83 (0.47, 1.46)	0.91 (0.45, 1.85)
Other	49 (6)	34 (69)	0.94 (0.48, 1.86)	0.56 (0.23, 1.32)
<i>Number of living children</i>				
0–1	83 (11)	45 (54)	1.00 (ref)	**
2–4	369 (48)	237 (65)	1.54 (0.95, 2.49)	
5+	309 (41)	202 (66)	1.61 (0.98, 2.63)	
<i>Years attending TASO</i>				
Less than 6 months	342 (44)	199 (58)	1.00 (ref)	1.00 (ref)
6 months–2 years	236 (30)	153 (65)	1.34 (0.95, 1.89)	1.47 (0.94, 2.31)
More than 2 years	198 (26)	140 (71)	1.80 (1.23, 2.62)*	2.49 (1.45, 4.27)*
<i>Type of most recent sexual partner</i>				
Spouse	522 (67)	387 (74)	1.00 (ref)	**
Steady	157 (20)	76 (48)	0.33 (0.23, 0.47)*	
Casual	103 (13)	35 (34)	0.18 (0.11, 0.28)*	
<i>Discussed sexual issues with partner</i>				
Yes	659 (84)	439 (67)	1.00 (ref)	1.00 (ref)
No	124 (16)	59 (48)	0.45 (0.31, 0.67)*	0.77 (0.48, 1.23)
<i>Condom use</i>				
Never	280 (36)	145 (52)	1.00 (ref)	1.00 (ref)
Sometimes	216 (28)	153 (71)	2.24 (1.54, 3.27)	2.00 (1.26, 3.16)
Always	285 (36)	199 (70)	2.14 (1.51, 3.02)	1.98 (1.25, 3.16)
<i>Partner's HIV status</i>				

Table 3 continued

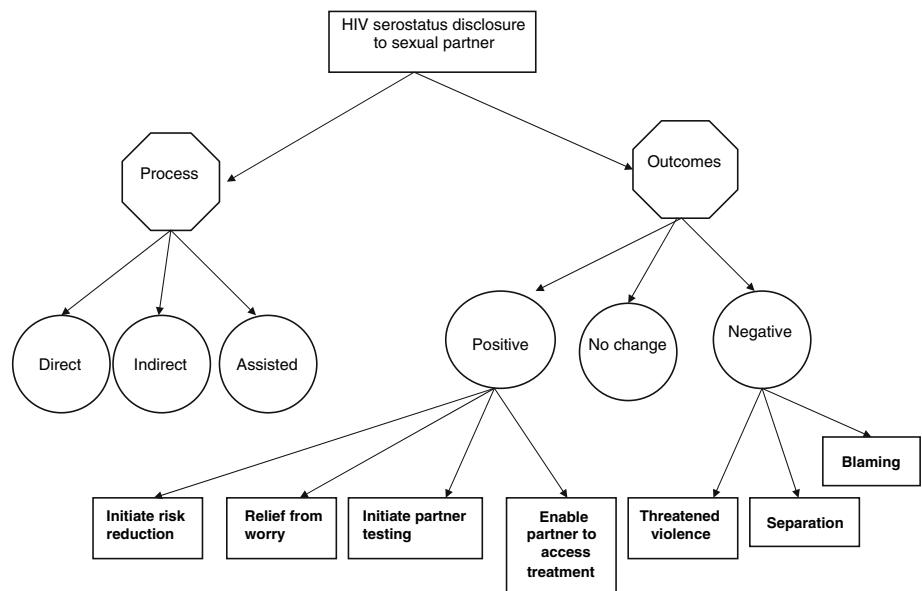
Socio-demographic characteristic	N (%)	Disclosure prevalence (overall = 64%)	Unadjusted OR [†] (95% CI)	Adjusted OR [†] (95% CI)
Don't know	477 (61)	219 (46)	1.00 (ref)	1.00 (ref)
Positive (tested)	241 (31)	222 (92)	13.77 (8.33, 22.74)*	10.93 (6.39, 18.70)*
Negative (tested)	63 (8)	57 (90)	11.19 (4.74, 26.46)*	7.83 (3.16, 19.41)*
<i>Sexually active in past 3 months</i>				
Yes	455 (58)	310 (69)	1.00 (ref)	1.00 (ref)
No	329 (42)	188 (57)	0.611 (0.46, 0.82)*	0.80 (0.54, 1.21)
<i>Years since first HIV+ test result</i>				
Less than 6 months	280 (36)	163 (58)	1.00 (ref)	**
6 months–2 years	218 (28)	138 (64)	1.25 (0.87, 1.81)	
More than 2 years	280 (36)	193 (69)	1.63 (1.15, 2.31)	
<i>WHO clinical stage</i>				
Stage 1	353 (45)	221 (63)	1.00 (ref)	1.00 (ref)
Stage 2	191 (25)	128 (67)	1.19 (0.82, 1.72)	1.37 (0.86, 2.17)
Stage 3	226 (29)	140 (62)	0.95 (0.67, 1.34)	1.28 (0.83, 1.97)
Stage 4	9 (1)	5 (56)	0.73 (0.19, 2.77)	1.14 (0.24, 5.54)

[†] Maximum likelihood estimates from logistic regression

* $P \leq 0.05$

** Not included in the adjusted model

Fig. 1 Conceptual framework on HIV serostatus disclosure—qualitative study on techniques and outcomes; 33 participants in qualitative study who disclosed (17 women and 16 men)



Several men and women who had not disclosed envisioned an assisted or supported disclosure process using TASO counselors. One woman, who had separated from her husband, asked a counselor to disclose for her so that her spouse would not infect other women. Some clients recommended that, in addition to supporting the disclosure process, TASO could assist in testing and counseling their partners. For example, a 51 year-old man stated, “I

would like TASO to visit my home and test all my wives”.

Many individuals refrained from disclosing to their sexual partners after learning of their HIV serostatus but instead suggested to their partners that they both be tested together. “I suggested to the doctor that he call both of us and retest us again; then disclose our status to us together” said one 58 year-old man.

Disclosure Outcomes and Experiences

Generally in-depth interview participants who had disclosed had more positive than negative outcomes (24 positive; 4 negative) while five reported no change in their relationship after disclosing. Twelve respondents who did not disclose reported fears of abandonment, abuse, and blame that might be associated with disclosure.

Barriers and Negative Outcomes: Fear of Abandonment, Abuse, and Blame

Although few participants who had disclosed actually experienced negative outcomes, normative fears were still a barrier to those who had not disclosed to their sexual partners. Women respondents conveyed anxiety around separation from sexual partners in relation to losing an important or sole source of income for herself and her children. Men also dread separation, often due to their worry about who will care for them and their children at home. In our qualitative sample, three women and one man experienced at least some period of separation related to disclosure. Of the three women, one left her husband after she disclosed because there was a history of violence in the relationship. Another woman experienced a 3-month separation with her husband, and when he came back, he tested, was found HIV-positive and became kinder and more loving to her than before. In the third case, her partner left her after she disclosed to him and she had not heard from him again. The man who experienced separation had three sexual partners who all responded differently: one left him, he mentioned increased sexual desire from the second, and the third did not believe the results. Fear of separation was a common normative disclosure barrier; “[A man] knows that immediately when [he] tells [his partner], she will pack her things and go back to her [parents] home. It would be so difficult for him to get another woman” (35-year-old man).

Concern about which member of the couple was first infected ran throughout the interviews as a significant barrier to disclosure for both men and women. Many believed that the partner who tests first and discloses will be seen as the one who was infected first. Fear of blame from the extended family was just as serious as from the partner him or herself. Blame was often associated with infidelity and accusations that lead to stigma and discrimination. As a 41-year-old woman who had not disclosed stated: “I cannot stand on my two legs and tell him that I have HIV, he will think that I am the one who infected him...in-laws can blame you for infecting [their] son, even though you did not deliberately do it. Even the villagers fear you; they accuse you of being a killer. The whole community can hate you and isolate you”.

Though stigma may be lower in Uganda than other African countries (UNAIDS 2001), many in-depth interview respondents (more men than women) expressed anxiety around stigma and discrimination especially when showing symptoms. Some had experienced stigma in the work place and from in-laws which led to hesitation around disclosure, but no client discussed discrimination resulting from a lived disclosure experience.

She [sexual partner] may go and tell everybody in public because of anger. She may even leave and tarnish my name and I lose market for my school and it is destroyed. I may get disrespect from the public...that is why I fear to disclose to her (58 year-old man who disclosed to first but not to second wife).

A significant barrier to disclosure, especially for women, was the fear of physical abuse by their partner. Ten of 24 women interviewed in depth mentioned having experienced violence related to sex, however none was associated with disclosure.

Motivations and Positive Outcomes: HIV Risk Reduction, Love, HIV Testing, Accessing Care and PMTCT

Of participants in the quantitative survey who disclosed, 87% stated it was not difficult. Many (16) individuals reported that the outcome of disclosing their HIV results to their partner included varied risk reduction measures (see Fig. 1). This was true of both men and women and of both those who disclosed directly or indirectly. Men and women who had disclosed said that one of the main reasons they had done so was to avoid transmission to their partner. They felt that disclosure would facilitate consistent condom use, abstinence, or other safer sex options within the couple. Respondents explained that in order to initiate safer sex options, it was important to first disclose their HIV status. They also reported that suggesting condom use without first disclosing can initiate mistrust, quarrels and misunderstandings in the home. The concept of reducing risk included re-infection to an already positive partner as re-infection was believed to be dangerous to the health of HIV-infected individuals. Of respondents in the qualitative sample who experienced positive outcomes, more than half specifically mentioned initiation of a risk reduction measure and some (both men and women) declared it a condition for staying together or continuing a sexual relationship as the following highlights:

He came to me for sex. I told him that I had tested positive for HIV, so if he was to have sex with me, he had to use condoms!... If he refused to use condoms, I

told him I would leave him and go back to my parents (33-year-old woman).

Risk reduction included initiation of condom use, reduction in numbers of partners or frequency of sex, or abstinence.

Four participants expressed strongly that disclosing HIV status was a sign of love for one's partner or resulted in increased caring or kindness by partner. They explained that disclosure can create open, honest channels of communication, and that disclosure shows trust and love for the partner as it also prevents further HIV transmission:

What I think about marrying somebody is that you should take that person the way he/she is and share all your fears and good things. So if you have a big problem like this [HIV] and you do not tell your wife, then it means there is no trust (35-year-old man).

Some couples mentioned increased kindness after disclosure.

As HIV testing is the entry point to services, a common reason for disclosure was to facilitate partner HIV testing and subsequently access to care and counseling (mentioned by 15 participants in qualitative interviews and 61 (5%) in the quantitative survey). According to one respondent, not disclosing “would be like running away from a leopard and not advising your friend to run away too” (34-year-old woman).

The relationship between testing, disclosure, and treatment is multi-dimensional and involves assumptions about prevalence of HIV infection and misunderstandings about discordance. Perceptions of high HIV prevalence and low levels of understanding on discordance appears to have facilitated disclosure as people believed their untested partners were HIV positive and should access medical care.

There are many positive results of disclosure. When you tell your partner your HIV status, she ... also goes for an HIV test and [if she] knows that she is also HIV-positive, she begins going for medical care. She starts looking after her body, feeding well, using condoms so that she doesn't acquire another strain of HIV (44-year-old man).

Disclosure of HIV positive status also allows the discloser to openly seek care at health facilities when sick. Without disclosing, it is difficult for someone without symptoms to explain the need to seek care and treatment either at home or at health facilities. In the quantitative survey this was the main reason for disclosure by both men and women. One respondent in the in-depth interviews mentioned that once you disclose, you will no longer have to get treatment secretly, but you could go together with your partner. Furthermore, some felt that disclosing HIV

status would enable partners to care for them when they fell sick.

I decided to disclose to her because of the way I was seeing her health condition yet we didn't have money to buy medicine ... even the health worker in Walukuba [testing centre] had advised me to tell her so that she is able to get treatment before she gets bad (18-year-old man).

Participants mentioned that having their partners know their HIV status relieved them from worry. Some were concerned that their partners might find out from someone else or on their own and that would be worse than telling them. Others, primarily men, were anxious that partners might think they died from witchcraft or an unknown cause, so they disclosed to enable their families to know the cause of death. One respondent stated that after disclosure one will live longer as a result of fewer worries.

Once HIV infection was disclosed openly, couples could plan for the future of the family. Men especially appeared to be concerned with planning as one 40-year-old man described: “I discussed it [HIV result] with my wife; ‘I am sick and you are not sick, what is the future of our family?’ We [can now] start planning... [if] you leave [the children] a house, you know they will not suffer for rent”.

In our qualitative sample, only two couples actually tested together for their first HIV test. They stated that receiving results together circumvented the potential blame associated with the member of the couple who tests first. In addition, many respondents who had not disclosed claimed that testing together as a couple would enable them to avoid possible blame and facilitate disclosure as this woman explained; “I had decided that if we remained together, since he accepted to use condoms, I would persuade him so that we go ... for HIV tests... you never know we might both be positive. He wouldn't know who got it from whom”. This strategy can also help discordant couples cope with their situation.

When prompted, many disclosed and non-disclosed respondents commented on the benefits of disclosure for preventing unwanted pregnancies and preventing mother-to-child transmission of HIV.

Discussion

Our study found that marital status, knowledge of partner serostatus and greater length of time in TASO were highly associated with disclosure highlighting the importance of couple communication. In addition, both our quantitative and qualitative findings suggest that in this population of HIV-infected persons in Uganda, HIV serostatus disclosure to sexual partner results in initiation of preventive sexual

behavior and increased care-seeking behavior. Positive outcomes resulting from disclosure included initiation of condoms use, reduction of sexual partners, testing and disclosure of sexual partners, accessing care for partner and self, relief from worry, and improved partner relationships.

Most participants did not experience negative outcomes after disclosure, but fear of these outcomes created disproportionate barriers to disclosure for those who did not tell their partners. These included fear of blame, abandonment, and violence, and were similar to findings from a study in Tanzania (Maman et al. 2003; WHO 2003). Clients who fear disclosing should be counseled to explore the reasons for their anxiety, and when indicated, referred to relevant services.

Contrary to other studies in Africa (Temmerman et al. 1995; WHO 2003) showing that disclosure comes with risk of negative outcomes, especially when there is a history of violence in the couple, there were no reports of violence associated with disclosure by women who had disclosed in our study. Our study found, as reported in other African countries, blame is a critical concept in disclosure as the member who tests first is often blamed for bringing the infection into the couple or family (Maman et al. 2001). Although only 6% of participants in this study had had couple testing and counseling, many highlighted the benefits of couple counseling during which both partners must face and address the dynamics surrounding blame, thereby hindering its negative consequences. Given the strong association between knowledge of partner status and disclosure, more widespread promotion of couples counseling could help obviate the need for disclosure interventions which often require multiple sessions. Couples counseling can also link these people to comprehensive, family-focused care and treatment opportunities.

Communicating directly is not the only or necessarily the best option for couples in Uganda, especially around sensitive topics such as sexuality. In our study, almost half the respondents disclosed their HIV serostatus indirectly and prepared their sexual partner through indirect methods that enabled a smooth and positive disclosure process. Counselors should be aware of this and openly assess with clients appropriate methods of disclosure that suit the clients' personal situation within his/her home and extended family. In Tanzania, disclosure has been described as a process that includes multiple decisions including when and how to disclose, to whom and under what conditions (Maman et al. 2003). Counselors can help in developing a personal disclosure plan that takes these steps into account.

Assisted disclosure, or having a friend or counselor help in the disclosure process, is a culturally appropriate method of conveying personal information in this setting. Similarly, a study among women in urban USA, showed that 14% of women reported that health care providers helped

them with disclosure to their sex partner (Gielen et al. 2000). Our study found comparable results and showed positive outcomes with supported disclosure (including condom use, decrease in numbers of partners, and partner testing) whether it was a friend or a counselor who helped in the disclosure process. This was especially true among clients who expressed hesitation around their own communication skills or fear of their partner's reaction.

AIDS prevention efforts in sub-Saharan Africa have mostly targeted HIV negative individuals and focused on messages to protect oneself from infection. Prevention with Positives (PWP) interventions shift the focus and aim at empowering HIV-positive individuals to prevent further infection to sexual partners and unborn children (Bunnell et al. 2006). PWP interventions have been widely implemented in the United States (Baskin et al. 2005), but far less so in Africa where prevalence of infection is high, HIV discordance is frequent, and the need for interventions is critical. Our findings suggest that disclosure of HIV status among this population was not as difficult as is often envisioned as 83% of our sample disclosed on the day they tested positive and 87% stated that it was not difficult to disclose. Disclosure can lead to positive prevention efforts and thus should be promoted in conjunction with the widely expanding care and treatment initiatives.

This study was limited by the fact that it only interviewed one member of the couples studied, thus could not validate reported responses or actions of the partner. Also, it was conducted among TASO clients, and it is unclear to what extent this group is representative of HIV-infected individuals not enrolled in an HIV care organization in Uganda. However, TASO currently has 50,000 members, and similar organizations exist in other African countries.

This population of HIV-infected Ugandans experienced benefits from sharing their HIV serostatus that outweighed negative experiences. Disclosure was frequent and helped HIV-infected individuals to increase the social support base to improve their medical management as well as to initiate risk-reduction behavior with partners of negative or unknown serostatus. Accessing medical and home care was the primary reason for disclosing among our survey participants, which highlights the importance of disclosure in expanding care and treatment services. Disclosure of HIV results also motivated sexual partners to seek voluntary HIV counselling and testing which is the entry point into all HIV care and treatment services. Sexual and reproductive health communication within the couple as well as heightened awareness of HIV transmission risk have widespread implications for preventive and care-seeking behavior change, which may ultimately reduce HIV transmission. Thus, post-test counseling of HIV-positive individuals should include clear messages on varied, client-centered, disclosure techniques and strategies to minimize

negative consequences and maximize the positive benefits of HIV serostatus disclosure.

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