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Early HIV disclosure and nondisclosure among men and women on antiretroviral treatment in Uganda

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Abstract

Efforts to expand access to HIV care and treatment often stress the importance of disclosure of HIV status to aid adherence, social support, and continued resource mobilization. We argue that an examination of disclosure processes early in the process of seeking testing and treatment can illuminate individual decisions and motivations, offering insight into potentially improving engagement in care and adherence. We report on baseline data of early HIV disclosure and non-disclosure, including reasons for and responses to disclosure from a cohort of men and women (n=949) currently accessing antiretroviral treatment in two regions of Uganda. We found early disclosures at the time of suspicion or testing positive for HIV by men and women to be largely for the purposes of emotional support and friendship. Responses to these selected disclosures were overwhelmingly positive and supportive, including assistance in accessing treatment. Nonetheless, some negative responses of worry, fear, or social ostracism did occur. Individuals deliberately chose to not disclose their status to partners, relatives, and others in their network, for reasons of privacy or not wanting to cause worry from the other person. These data demonstrate the strategic choices that individuals make early in the course of suspicion, testing, and treatment for HIV to mobilize resources and gain emotional or material support, and similarly their decisions and ability to maintain privacy regarding their status.

Keywords

HIV treatment; disclosure; Uganda

Introduction

Efforts to expand access to HIV treatment stress the importance of HIV disclosure to access social support and resources needed to maintain treatment (Klitzman et al., 2004; Stirratt et al., 2006). For HIV-infected individuals disclosure remains a double-edged sword that may gain material resources while simultaneously creating conflict, stigma, shame or discrimination. HIV disclosure is a process that changes across the disease spectrum, with individual needs, relationships, and disease progression- it may include deliberate acts of telling or not telling (Antelman et al., 2001; Bond, 2010; McGrath et al., 2009). We refer to

disclosures immediately following suspicion of infection, testing, or diagnosis as ‘early disclosures.’ We examine early disclosures and intentional non-disclosures among men and women receiving antiretroviral treatment in two regions of Uganda.

Background

The disclosure process

Research on HIV disclosure identifies factors influencing disclosure and its outcomes, including individual, psychosocial, and clinical benefits (Almeleh, 2006; Shisana et al., 2005), and potential harm, stress, or stigma (Gilbert & Walker, 2010; Holt et al., 1998; Simbayi et al., 2007). Women more frequently disclose or are disclosed to (Medley et al., 2009; Obermeyer, Baijal, & Pegurri, 2011). Reasons for disclosure include material or emotional support, visible symptoms, proximity in living space, moral responsibility, or a sexual relationship (Klitzman & Bayer, 2003; Ndiaye et al., 2008; Simoni and Pantalone, 2004).

Recently, disclosure research incorporates considerations of changing needs and individual negotiation of disclosure decisions (Bond, 2010; Siegel and Schrimshaw, 2005). Proponents of disclosure stress its importance for medication adherence and consequent secondary prevention (Birbeck et al., 2009; Klitzman et al., 2007).

Uganda

In Uganda, approximately 940,000 people are living with HIV, with adult prevalence rates ranging from 5.4% to 7.3% (Uganda, 2008, 2012; UNAIDS, 2010). Countrywide, women have higher HIV prevalence than men. Urban residents have higher prevalence than rural residents. Today, 53% of those needing antiretroviral therapy in Uganda currently receive it, however, under new recommendations to begin ARVs at lower CD4 counts, estimates are for 34% coverage (UNAIDS 2010; UNITAID 2010).

Methods

We present data from a longitudinal, mixed methods study of the social context of HIV treatment in Uganda. The study examined experiences of HIV infected participants over 24 months in two regions: Kampala City and Mbarara in Southwestern Uganda (n=949). Semi-structured interviews covered: demographics, illness history, adherence, and treatment experiences. This paper reports data from baseline interviews conducted between September 2008 and July 2009.

Study population and recruitment

Within Kampala, participants were recruited at the Joint Clinical Research Centre (JCRC). In Mbarara, participants were recruited through the Immune Suppression Syndrome (ISS) clinic of Mbarara Hospital.

Participants were age 18 or older and had been receiving antiretroviral treatment for at least 6 months when they began the study. A counselor referred every third eligible client to the research assistants who administered consent.

Ethical considerations

Ethical approval was granted by the Institutional Review Boards at Case Western Reserve University, the JCRC, Mbarara University, and the Uganda National Council of Science and Technology. All participants gave written informed consent in Luganda, Runyankole-Rukiga, or English.

Data management and analysis

Interviewers translated and transcribed responses during the interview. Qualitative analyses were performed using a content analysis approach. Two independent observers coded responses for key themes. Ten percent of responses were dual-coded to ensure inter-coder reliability. Descriptive and bivariate analyses were performed in SPSS to compare distributions by site and gender.

Results

Demographics

Table 1 presents demographic characteristics of participants. By design, the sample is evenly divided by sex and location. The average age was 38.2 years (range 18–65, SD 8.51). Most participants are married (53.8%). Significantly more participants in Mbarara (58.3%) report being married or cohabiting than in Kampala (49.5%) ($p < .05$). Most participants report being employed, though significantly more in Kampala than Mbarara ($p < .05$). Overall, participants report an average of 3.5 children (range 0–18, SD 2.56) and an average of 5.3 household members (range 1–26, SD 3.12); households in Kampala (5.74) were significantly larger than in Mbarara (4.92) ($p < .05$).

Experiences of early disclosure

Participants listed persons to whom they disclosed when they first suspected infection, whether or not they had tested yet (Table 2). The most common targets for early disclosure were siblings (28.3%), spouses (23.3%), friends or neighbors (14.5%) and parents (12.6%). Participants in Kampala were significantly more likely than those in Mbarara not to discuss early suspicions with anyone ($p < .05$). Men were significantly more likely than women to disclose to partners or workmates, but significantly less likely to disclose to children or siblings ($p < .05$).

Participants were asked how these individuals reacted when disclosed to (Table 3). The most frequent response was active support (34.1%), including emotional and material resources—significantly more frequent in Kampala (45.2%) than Mbarara (23.6%) ($p < .05$). Other responses include fear or worry (32.7%), assistance in accessing treatment (28.0%), or acceptance (11.5%). Some experienced extreme negative responses (5.3%), including being asked to leave home, or verbal abuse. This was significantly more common in Kampala than in Mbarara ($p < .05$). There were no significant differences between men and women in reported responses to early disclosure.

Reasons for disclosure

Reasons for disclosure of HIV status vary based on circumstances and relationships (Table 4). Individuals disclosed to persons who lived with them or could provide support (32.9%), friends (14.4%), someone who could provide medical resources (8.1%), if they wanted the person to know (6.5%), because they felt obligated to a sexual partner (6.1%), were afraid not to disclose (5.0%), or the person was also HIV positive (2.8%). Women were more likely to disclose due to ‘fear’ than men ($p < .05$); men were more likely than women to disclose to access medical resources ($p < .05$).

Intentional Nondisclosure

Participants were asked who they have *not* told about their HIV status and why. The question was framed to identify persons who participants specifically did not want to know about their HIV status, rather than those who they had simply not told yet (Table 5). The most common responses were: friends/ neighbors (16.5%), parents (15.2%), children

(15.0%), and other relatives (13.6%). Participants in Kampala were more likely than in Mbarara to have deliberately not told their friends/neighbors, children, and other relatives; men were more likely than women to have not disclosed to workmates ($p < .05$).

Reasons for nondisclosure

Reasons for nondisclosure also varied by relationship and individual circumstances (Table 6). These included viewing HIV status as a private matter (29.0%), fear of stigma (23.3%), desire not to hurt others (19.4%), lack of opportunity to tell (15.1%), or feeling that the person was too young (14.0%) or too old (5.5%) to be told. Men were more likely to report “too young” as the reason for nondisclosure ($p < .05$). People in Kampala were more likely to list potential negative effects to others and being too young as reasons for nondisclosure ($p < .05$); participants in Mbarara more often cited privacy as their reason for nondisclosure ($p < .05$).

Discussion

In this paper, we focus on intentional early disclosure or non-disclosure of HIV status. By exploring disclosure decisions beginning at the time of suspicion of HIV infection, these data highlight disclosure early in the disease spectrum. Early disclosures to spouses, siblings, and relatives, garnered emotional support and friendship, although reasons to disclose vary widely (Ssali et al 2010; Serovich 2001). We found no significant gender differences in reported responses to disclosure, despite literature citing greater risks for women (Duff et al., 2010; Kairania et al., 2010; Medley et al., 2009). Both genders reported few negative responses.

Most participants reported withholding known HIV status for privacy or to *protect others* because HIV status of one member of a social network may stigmatize another. Nondisclosure is not always stigma related, however; there is simply no reason to tell anyone outside of one’s immediate network. Within networks, individuals deemed too young, too old, or likely to gossip may be excluded from disclosure. Clearly these decisions are situational.

Limitations

Several limitations should be considered when interpreting these results. Retrospective data on disclosure may not capture all early disclosures, as individuals may not recall everyone with whom they discussed their suspicion. Second, these data do not show the disclosure process over time. Follow up data in this cohort will assess ongoing disclosures and nondisclosures. Additionally, results from participants with access to treatment may not be generalizable to the HIV positive population in Uganda as a whole.

Conclusions

HIV infected persons make strategic decisions regarding selective early disclosure and nondisclosure, disclosing primarily to those physically and socially closest to them. Treatment can prompt disclosure so as to marshal resources needed for treatment but also protects from inadvertent disclosures by decreasing visible symptoms that make others aware of the diagnosis. As illness progresses, however, increased demand for resources to maintain treatment may result in disclosures to more distant social network members. Understanding how patterns of disclosure relate to social relationships and circumstances can help improve engagement in care. Therefore, recognizing the importance of strategic disclosure and nondisclosure may help better serve HIV patients.

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Table 1

Demographics

	Kampala (N = 481)		Mbarara (N = 468)	
	N	(%)	N	(%)
Sex				
Male	242	(50.3)	233	(49.8)
Female	239	(49.7)	235	(50.2)
Marital Status *				
Married	238	(49.5)	273	(58.3)
Divorce/separated	67	(13.9)	61	(13.0)
Widowed	115	(23.9)	99	(21.2)
Single	61	(12.7)	35	(7.5)
Employed *				
Yes	337	(70.1)	277	(59.2)
No	144	(29.9)	191	(40.8)

* significantly different by site (Chi square: $p < .05$)

Table 2

Responses to: 'When you first suspected that you had HIV/AIDS who did you tell/ discuss this with?'

	Total N=947 n(%)	Kampala N=479 n(%)	Mbarara N=468 n(%)
Siblings⁺	268(28.3)	136(28.4)	132(28.2)
Spouse⁺	221(23.3)	94(19.6)	127(27.1)
No one[*]	148(15.6)	99(20.7)	49(10.5)
Friends/neighbor	137(14.5)	57(11.9)	80(17.1)
Parents	119(12.6)	52(10.9)	67(14.3)
Other relatives	100(10.6)	45(9.4)	55(11.8)
Children⁺	63(6.7)	24(5)	39(8.3)
Health Care Provider	24(2.5)	12(2.5)	12(2.6)
Workmates⁺	18(1.9)	7(1.5)	11(2.4)
Other people	11(1.2)	6(1.3)	5(1.1)

^{*} significantly different by site (Chi square: $p < .05$)

⁺ significantly different by gender (Chi square: $p < .05$)

Table 3

Reactions to disclosure

	Total N=819 n(%)	Kampala N=396 n(%)	Mbarara N=423 n(%)
Support *	279(34.1)	179(45.2)	100(23.6)
Afraid /worried	268(32.7)	138(34.8)	130(30.7)
Treatment *	229(28.0)	67(16.9)	162(38.3)
Acceptance	94(11.5)	40(10.1)	54(12.8)
Extreme Negative *	43(5.3)	30(7.6)	13(3.1)
Other	19(2.3)	10(2.5)	9(2.1)

* significantly different by site (Chi square: $p<.05$)

Table 4

Reasons for disclosure

	Total N=929 n(%)	Kampala N=468 n(%)	Mbarara N=461 n(%)
Support/Lived with	306(32.9)	157(33.5)	149(32.3)
Trust/Friend *	134(14.4)	88(18.8)	46(10.0)
Medical resources * +	75(8.1)	26(5.6)	49(10.6)
Wanted them to know *	60(6.5)	12(2.6)	48(10.4)
Partner	57(6.1)	32(6.8)	25(5.4)
Fear * +	46(5.0)	35(7.5)	11(2.4)
Relatives	46(5.0)	26(5.6)	20(4.3)
HIV positive	26(2.8)	12(2.6)	14(3.0)
Asked/lived nearby	14(1.5)	7(1.5)	7(1.5)
Other	76(8.2)	32(6.8)	44(9.5)

* significantly different by site (Chi square: $p < .05$)

+ significantly different by gender (Chi square: $p < .05$)

Table 5

Who have you not told that you were HIV infected?

	Total N=831 n(%)	Kampala N=465 n(%)	Mbarara N=366 n(%)
Friends/neighbor *	156(16.5)	105(21.9)	51(10.9)
Parents	144(15.2)	70(14.6)	74(15.8)
Children *	142(15.0)	107(22.3)	35(7.5)
Other relatives *	129(13.6)	86(18)	43(9.2)
Other people *	70(7.4)	12(2.5)	58(12.4)
Siblings	62(6.5)	33(6.9)	29(6.2)
Non-family *	53(5.6)	9(1.9)	44(9.4)
Spouse	38(4.0)	23(4.8)	15(3.2)
Workmates ⁺	37(3.9)	20(4.2)	17(3.6)

* significantly different by site (Chi square: $p < .05$)⁺ significantly different by gender (Chi square: $p < .05$)

Table 6

Reasons for nondisclosure

	Total N=670 n(%)	Kampala N=357 n(%)	Mbarara N=313 n(%)
Not necessary/ Private *	194(29.0)	70(19.6)	124(39.6)
Fear of Stigma	156(23.3)	78(21.8)	78(24.9)
Neg. Effects on others *	130(19.4)	82(23.0)	48(15.3)
Not close/No chance to tell	101(15.1)	53(14.8)	48(15.3)
Too Young * +	94(14.0)	69(19.3)	25(8.0)
Too Old	37(5.5)	19(5.3)	18(5.8)
Gossip	28(4.2)	19(5.3)	9(2.9)
Other	42(6.3)	20(5.6)	22(7.0)

* significantly different by site (Chi square: $p < .05$)

+ significantly different by gender (Chi square: $p < .05$)