

HIV status disclosure to families for social support in South Africa (NIMH Project Accept/HPTN 043)

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Literature on HIV status disclosure among persons living with HIV/AIDS (PLWHA) is dominated by research on the rates, barriers and consequences of disclosure to sexual partners, because of the assumed preventive health benefits of partner disclosure. Disclosure of HIV status can lead to an increase in social support and other positive psychosocial outcomes for PLWHA, but disclosure can also be associated with negative social outcomes including stigma, discrimination, and violence. The purpose of this article is to describe the HIV status disclosure narratives of PLWHA living in South Africa. Thirty in-depth interviews were conducted with 13 PLWHA (11 women, 2 men) over a three-year period. We explored disclosure narratives of the PLWHA through questions about who they chose to disclose to, how they disclosed to these individuals, and how these individuals reacted. Narratives focused on disclosure to family members and contained relatively little discussion of disclosure to sexual partners. Participants often disclosed first to one trusted family member, and news of the diagnosis remained with this person for a long period of time, prior to sharing with others. This family member helped the PLWHA cope with the news of their diagnosis and prepared them to disclose to others. Disclosure to one's partner was motivated primarily by a desire to encourage partners to test for HIV. Two participants described overtly negative reactions from a partner upon disclosure, and none of the PLWHA in this sample described very supportive relationships with their partners after disclosure. The critical role that family members played in the narratives of these PLWHA emphasizes the need for a greater focus on disclosure to families for social support in HIV counseling protocols.

Keywords: South Africa; disclosure; HIV/AIDS; social support

Introduction

Disclosure of HIV status among people who test positive for HIV has important implications for preventing new HIV infections and for the treatment, care and support of people living with HIV/AIDS (PLWHA) (Pinkerton & Galletly, 2007). The potential preventive health benefits of disclosure have been emphasized in health research and programs (Maman et al., 2003; Sachperoglou & Bor, 2001; Skhosana, Struthers, Gray, & McIntyre, 2006; Skogmar et al., 2006; Smith, Rossetto, & Peterson, 2008; UNAIDS, 2000) with a particular focus on HIV disclosure to sexual partners (Medley, Garcia-Moreno, McGill, & Maman, 2004).

There is mixed evidence that disclosure to sexual partners leads to sexual risk behavior change (Hart, Wolitski, Purcell, Parsons, & Gómez, 2005; King et al., 2008; Marks & Crepaz, 2001; O'Brien & Kissinger, 2002; Olley, Seedat, & Stein, 2004; Weinhardt et al., 2004). Negative social outcomes of disclosure to partners including blame, stigma, discrimination, and violence are not reported widely, yet fear of these outcomes continue to be barriers for HIV-infected

individuals who have not disclosed (Crosby, Bonney, & Odenat, 2005; Ezechi et al., 2009; King et al., 2008; Sayles, Ryan, Silver, Sarkisian, & Cunningham, 2007).

Few studies explore the experiences and outcomes of HIV status disclosure to family members, particularly in settings that bear a disproportionate burden of the HIV epidemic, like South Africa. Research from the USA suggests that family members are often the primary targets for disclosure (Serovich, Craft, & Yoon, 2007; Sowell, Seals, Phillips, & Julious, 2003).

Disclosure of HIV status can result in social support for PLWHA when family and friends react positively to the news of their diagnosis (Grinstead, Gregorich, Choi, & Coates, 2001; Kalichman, DiMarco, Austin, Luke, & DiFonzo, 2003; Sachperoglou & Bor, 2001; Smith et al., 2008). Disclosure of HIV status to family and friends has also been shown to improve the management of HIV among PLWHA, including greater adherence to antiretroviral therapy (ART) (Aggleton, Wood, Malcolm, & Parker, 2005; Klitzman et al., 2004; Mukherjee, Ivers, Leandre, Farmer, & Behforouz, 2006; Nam et al., 2008; Stirratt et al., 2006; Varga, Sherman, & Jones, 2006).

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Given the emphasis on HIV testing and treatment in Africa, we need to better understand how PLWHA manage the news of their diagnosis and reach out to others in their network for support. The purpose of this article is to describe the HIV disclosure narratives and the role that family members play in the narratives of 13 individuals living with HIV/AIDS in South Africa.

Methods

The data for this study comes from South African communities participating in NIMH Project Accept (HPTN 043), a community randomized trial conducted in the two South African sites, and sites in Tanzania, Thailand, and Zimbabwe. The trial took place during 2005–2011 and was designed to measure the efficacy of a community-based model of voluntary HIV counseling and testing (Khumalo-Sakutukwa et al., 2008). In South Africa, the study was conducted in two sites. The first site, Soweto, is the largest, most densely populated township in South Africa. The township was created to accommodate the workforce for Johannesburg. The second site, Vulindlela is a sub-district within the rural KwaZulu-Natal midlands region, situated about 150 km west of Durban with a total population of approximately 500,000 people. The HIV prevalence is greater than 10% in both settings (Shisana et al., 2009).

The qualitative component of Project Accept comprised of a longitudinal sample of community members, who had been previously randomly selected for the baseline survey at each site. To be eligible, participants had to be between 18 and 32 years (the ages associated with the highest risk for HIV in most of the sites), currently residing and planning on remaining in study communities for at least three years. To select participants, we stratified the baseline sample into a combination of eight demographic categories according to gender, age range split in half (18–24 years, 25–32 years), and partner status (single or coupled). We randomly selected two participants per demographic category in each of the communities resulting in a sample of 109 individuals in Soweto and 126 in Vulindlela. We conducted interviews with each participant – at baseline, and at 6, 15 and 30 months after the intervention launch. Ethical approval for this study was secured from South African and US institutional review boards representing each site. All individuals provided voluntary, written informed consent prior to study participation.

Semi-structured in-depth interviews were based on a standard field guide that was used across the sites.

Trained interviewers conducted 30–60 minute interviews in the local language. A component of the interview focused on the HIV testing and disclosure experiences of previously tested individuals. Participants were not asked to reveal their HIV status; however, during the course of the interviews seven individuals from Soweto and six from Vulindlela disclosed their HIV positive status to the interviewer. To the extent that these participants were comfortable, the interviewers asked for details about their experiences learning their diagnosis and sharing their status with others. We focused on the narratives from the South African sites for this article, because the majority of PLWHA who self-disclosed were from these sites. We have a complete set of four interviews from two of the individuals, a set of three interviews from four individuals, two interviews from another three individuals and the baseline interview only for four individuals. This amounts to a total of 30 interviews for the 13 individuals included in this analysis.

The 30 interviews were audiotaped, transcribed and translated into English for analysis. Interviews were coded in Atlas.ti (version 5.2). Thematic data analysis was conducted in two phases. In the first phase, we applied descriptive codes (Miles & Huberman, 1994) to the HIV testing and disclosure narratives of the sample. Our codebook included a detailed description of each code and sub-code, as well as inclusion and exclusion criteria (MacQueen, McLellan, Kay, & Milstein, 1998). Qualitative staff at each site were trained to code in Atlas.ti. All research staff were trained and certified to code prior to beginning the coding process, and coding was systematically reviewed according to a protocol at each site. Problems with coding were addressed at site prior to merging coded data for analysis.

In the second phase of analysis we compared the discussion about testing and disclosure over time and across participants through the use of a matrix (Miles & Huberman, 1994). A chronology of events was developed for each case and compared across the cases through the matrix (Saldana, 2003). The matrix was created by the primary author and shared with the co-authors, and with qualitative research staff from the sites in two qualitative research writing workshops to describe the patterns that emerged within and across the narratives.

Results

Participants' narratives on disclosing their HIV status focused predominantly on disclosing to family members and contained relatively little information on

disclosure to sexual partners. Therefore, in the results section, we start by describing the patterns and outcomes of disclosure to family members. Next, we describe how some participants selectively concealed their HIV status from some family members and finally, we describe patterns and outcomes of disclosure to sexual partners.

Description of the sample

Thirteen individuals who self-disclosed as HIV positive are included in this analysis, seven (six women, one man) from Soweto and six (five women, one man) from Vulindlela. Among the 11 women, seven reported that they had a primary sexual partner (defined as someone they had been with for at least six months) and the majority were older than 25. Among the two men, one was single and one had a primary partner, and both were older than 25. Most of the participants (11/13) had been diagnosed with HIV prior to the baseline interview; however, two individuals learned about their diagnosis during the study. Six of the women learned of their diagnosis during pregnancy. The two men were tested for HIV when they went to a clinic for services related to a specific health condition.

Patterns and outcomes of disclosure to family

Among these 13 PLWHA, there was only one individual who had not disclosed her results to anyone, and she had known of her status for four years. Every other participant had shared their diagnosis with at least one person, and most participants had disclosed to several people.

Ten PLWHA had disclosed their status to someone in their family and many did so because they felt there was “nothing more important than getting family support.” In several cases, the PLWHA chose their sister, mother or aunt as the first target for disclosure and then waited for a long period of time before disclosing to anyone else. One woman who learned of her HIV status two years prior to the baseline interview said she had only ever disclosed to her younger sister and that it took her a year to do so. She decided to disclose because:

It's just that I trust her. I tell her everything. She keeps my secrets because until today it is only her and me that know.... She does not have a problem, others, I thought [participant is crying] maybe they will discriminate me...

One of the male participants who learned about his HIV status between the baseline and 6-month interviews only disclosed to his sister by the 15-month

interview. By the time of the 30-month interview he reported that he had disclosed to other family members, but not to anyone outside of the family.

Participants who shared the news of their diagnosis with family described an enormous sense of relief. This woman, who had concealed her status for three years before first sharing her diagnosis with her mother and then other members of her family, describes the sense of freedom that she experienced after she disclosed:

After I told her I lived a normal life and was free. I didn't have anything to hide. After they knew that I was positive that is when I lived my life, my positive life. As to how they looked at me, I didn't care as long as this thing is out in the open.

Four participants did not disclose to anyone in their family for a long time. Illness eventually compelled them to share their results with family. One participant said it took her three years before she disclosed her status to her family. It was not until she suffered from a case of shingles that she and her partner decided to disclose their HIV positive status to their families. She said, her partner became scared, “He thought what if this thing continues and something happens to me that means it will be his secret and we haven't told anyone.”

Reasons for selectively concealing HIV status from family members

Three participants had not disclosed to anyone in their family, and others concealed their HIV status from some family members. Much of the discussion in their disclosure narratives focused on the tension and anxiety they experienced in concealing their HIV status from family members. A woman who learned about her HIV status between the baseline and 6-month interviews described a very supportive relationship with her family. However, by the time of the 30-month interview she still had not shared her HIV diagnosis with her mother, because she was worried about her mother's health. She acknowledged that, “If I can tell my family first, it wouldn't matter what the community would say.” Other participants who had not told certain family members were also motivated by a desire to protect their family member's emotional and physical well-being. A woman who had known about her HIV status for several years had not yet disclosed to her mother. She says, “I am afraid of telling my mother because I know that she is someone who is fearful. She is someone who is overcome by emotions.”

Patterns and outcomes of disclosure to sexual partners

Among the 13 participants, eight had shared their HIV diagnosis with a sexual partner. Four of the eight individuals who had a primary sexual partner had disclosed to their primary partner. Three participants reported having multiple partners, and only one of these individuals had disclosed their status to all their partners. In all cases except for one, the PLWHA disclosed to family members before sharing their results with their partner.

The participants' motivations for disclosing to their sexual partners differed from their motivations for disclosing to family members. Four of the eight participants who had disclosed to sexual partners did so as encouragement for their partner to get tested. Only one of these partners subsequently got tested. In this case the woman learned of her positive diagnosis during pregnancy. She did not tell her partner she had tested positive. Instead, she told him that the clinic wanted to test both of them together. When they went to the clinic, she tested again with her partner. It was in the context of this testing experience that he learned of his negative HIV status and her positive diagnosis.

Among the participants who had not disclosed to their partner, the reasons they gave for non-disclosure included fear of a "short temper," and concern that partner could not be trusted with the "secret." One of the male participants who knew about his status for four years, said that the time to tell his partner "has not arrived," though they have been together for three years.

Among the women who did disclose to their partner, none described a supportive reaction from their partner. Two women described overtly negative reactions from partners. The woman mentioned above whose partner learned of their discordant status when they tested together during pregnancy describes his reaction:

Maybe I shouldn't have told him because at first he wasn't fine with everything, you understand that you are negative and your partner is positive. He started being violent and then I said to him. 'Good luck if you see that I'm the one who came with it.' Anyway I'm not going to blame you. You are not my first boyfriend. Maybe I was your first girlfriend, although I know I wasn't your first girlfriend. You had a relationship before.

Discussion

The disclosure narratives from these PLWHA were dominated by reflections about how, when and what their experiences have been disclosing their HIV status to family members. The social support function

of HIV status was emphasized to a far greater extent than the potential preventive role of disclosure to sexual partners. Having one family member whom they could trust was an important first step for PLWHA. In these narratives, knowledge of HIV status sometimes remained with this trusted family member for a long time before the individual disclosed to others. This person played a critical role in providing emotional support as the PLWHA came to term with their status, and helped the PLWHA share their diagnosis with others. Miller found a similar pattern among individuals testing positive for HIV in Nairobi, Kenya. Participants in this setting described, carefully selecting a relative with whom they were close to initially reveal their status, even before informing their spouse. This relative was someone they trusted to keep the secret, and who could play an intermediary role in helping them share results with others (Miller & Rubin, 2007).

What is striking from these disclosure narratives is the absence of discussion about disclosure to sexual partners. Disclosure to partner was motivated primarily by a desire to encourage partners to test for HIV and learn their own diagnosis. Even though only two participants described an overtly negative reaction from a partner upon disclosure, none of the PLWHA in this sample described supportive relationships with their partners after disclosure.

These findings lend support to the ideas of social exchange theorists, who maintain that people maximize the profits of their relationships by avoiding those relationships that will cost them the most socially, emotionally, or otherwise, and they seek out relationships that will maximize these dimensions (Serovich, 2001; Thibaut & Kelley, 1959). Using this approach, PLWHA in this sample weighed the anticipated costs and benefits when deciding whether or not to disclose to their family, friends, or partners (Derlega, Lovejoy, & Winstead, 1998). The process of reducing risks and increasing benefits of disclosure results in the kind of patterns of selective disclosure that we found. Individuals disclosed to those whom they perceived would offer support, while avoiding disclosure to those whom they perceived would harm them.

These data are not without limitations. First, only 13 individuals from these two sites self-disclosed as HIV-positive. Given the very high HIV prevalence in these settings, it is very likely that other HIV-positive participants in the qualitative cohort were either not aware of their HIV status, or did not feel comfortable self-identifying as HIV infected. These individuals, who were willing to talk openly about their diagnosis might be more likely to have come to terms with their status and to have received support from those that

they disclosed to, which enabled them to talk openly about their diagnosis. Second, there is a gender difference in the individuals who self-identified as HIV infected. Only two of the 13 individuals who self-identified as HIV infected were men in this study; therefore, the experiences of men are not adequately captured in these data. Finally, we had a variable number of interviews for each participant. Whereas the longitudinal nature of the collected data enabled us to follow up on important themes over time, it is possible that the experiences of the participants with more interviews in this data-set were overrepresented in the analysis.

These findings need to be understood in the context of South Africa, where marriage rates are very low and long-term stable sexual partnerships are not the prevailing norm for a range of historical and cultural reasons (Hunter, 2002, 2007; Montgomery, Hosegood, Busza, & Timaeus, 2006). In 2001, less than 30% of African men and women over 15 years of age in South Africa were married. Low wages and high unemployment make it difficult for men to live up to the socially defined role as providers. These trends have important implications on the ability of men to be positively involved with households, and might drive men away from familial responsibilities and engagement (Campbell, 1992; Smit, 2002). Whereas a direct causal relationship between declining marriage rates and increased number of sexual partners has not been established, it is likely that the decline in formal marital relations and a concomitant rise in women's economic independence have had an impact on partners' commitment to one another (Hunter, 2002; Motsemme, 2007). The changing nature of sexual relationships might help to explain why the participants focus on their experiences of sharing results with family. Family members in these narratives play an important and ongoing role in the lives of these PLWHA.

Currently, international guidelines and protocols for HIV counseling and testing emphasize disclosure to sexual partners for risk reduction. While this is important, these data suggest that our counseling protocols need to be reframed to place greater emphasis on disclosure for social support since individuals in our study who did not have the support of their family members were often less likely to disclose to their sexual partners. Counselors can help PLWHA identify targets, whom they feel they can trust for early disclosure, as these data suggest that in many cases this will be a family member. Counselors can work with the individual to develop disclosure plans that involve using the trusted family member as an intermediary for disclosure to sexual partners and others. HIV positive individuals without supportive

families may need assistance identifying alternative sources of support. The critical role that family members played in the narratives of these PLWHA emphasizes the need for a greater focus on families and social support in HIV counseling and disclosure protocols and policy.

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