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Author Manuscript

Glob Public Health. Author manuscript; available in PMC 2014 July 07.

Published in final edited form as:

Glob Public Health. 2012 ; 7(8): 799–811. doi:10.1080/17441692.2012.679742.

HIV+ women's narratives of non-disclosure: resisting the label of immorality

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Abstract

Increasing partner disclosure rates among HIV positive individuals is widely seen as an important public health strategy to reduce HIV transmission. One approach for encouraging disclosure is to emphasize individuals' moral responsibility to disclose their status to their partners. We use South Africa as a case study to draw attention to two problems with labeling non-disclosure as immoral. First, we argue that because women are tested for HIV at much higher rates than men, any approach that involves blaming HIV positive individuals for not disclosing their status will disproportionately burden women. Second, through the narratives of six HIV positive women, we highlight how a focus on morality undervalues the complexity of sexual partnerships. Specifically, women describe how their perceived obligation to disclose is directly influenced by communication with their sexual partners. Women also discuss how the onset of different life events might alter the meaning of HIV and change obligations regarding disclosure within the partnership. The differences in testing rates across gender combined with the complexity of sexual partnerships leads us to suggest that labeling non-disclosure as immoral does little to advance HIV prevention. There is an urgent need to identify alternative interventions that support women through the disclosure process.

Keywords

ethics; qualitative methods; disclosure; HIV prevention; South Africa

Introduction

The public health community has engaged in numerous strategies to reduce the global spread of HIV over the last 30 years. Strategies specific to prevention of sexual transmission include increasing the numbers of individuals who get tested for HIV; decreasing high risk

sexual behaviour; and more recently, increasing access to treatment of HIV medication (Castilla et al. 2005; Coates et al. 2008; Gay and Cohen 2008; Lalani and Hicks 2007; Rotheram-Borus et al. 2009). Recent research and policy has also focused on “Prevention for Positives,” (Auerbach 2004; CDC 2001; Fisher and Smith 2009; Kennedy et al. 2010) which stresses the importance of disclosure of one’s HIV status and safe sexual behaviour of the individual following HIV testing, since from a disease control perspective, each new infection starts from an infected person (CDC 2001).

Concern about disclosure rates finds some support in the literature, though data are limited. A World Health Organization review paper on disclosure rates among women in seventeen developing countries found that between 16.7%–86% of women disclosed their HIV status to their sexual partner (Medley et al. 2004). Literature in South Africa suggests that between 22%–79% of individuals disclose their HIV status to their sexual partner up to three months after diagnosis (Makin et al. 2008; Olley et al. 2004; Skogmar et al. 2006; Varga et al. 2006). Though it is hard to draw meaningful conclusions about rates of disclosure given variability in study design, measurement and context, at a minimum, there are at least 14% of HIV+ individuals who do not disclose their HIV status to their primary sexual partner across these different studies, and these rates may be higher among South Africans.

There is continued debate about whether those who know they are HIV-infected need to inform their sexual partner(s) of their infection in order to protect the partner prior to engaging in sexual intercourse (Ainslie 1999; Bennett et al. 2000; Bruner 2004; Dixon-Mueller 2007; Dixon-Mueller and Germain 2007; Masiye and Ssekubugu 2008; O’Leary and Wolitski 2009; Symington 2009). In early HIV prevention discourse, strategies often focused on the “safer sex ethic.” All individuals who engaged in sexual intercourse were encouraged to assume their potential partner might be positive and act accordingly (Ainslie 1999). The discourse has changed, however, and responsibility of disclosure has been shifted to those who are already infected. This is most obviously evidenced by the growing number of countries and states that have criminalized non-disclosure when it results in transmission of HIV (Burris and Cameron 2008; Cameron 2009; Jurgens et al. 2009; UNAIDS 2009). Because criminal penalties connote some level of moral blame, these laws implicitly place a moral responsibility on people living with HIV/AIDS (PLWHA) to disclose their status to all of their sexual partners.

A recent article published by senior investigators at the Centers for Disease Control (CDC) reinforces the notion that HIV+ individuals have a moral obligation to disclose their HIV status. The article argues that individuals with low levels of “moral agency” may be more likely to engage in unsafe sexual behaviour and less likely to disclose their HIV+ status than individuals with high levels of “moral agency” (O’Leary and Wolitski 2009). It concludes that interventions for HIV+ individuals may be more effective in preventing transmission to others if they enhance “personal responsibility and promote strategies that prevent **moral disengagement.**” (pg. 490, emphasis added (O’Leary and Wolitski 2009)). Additionally, Ruth Dixon-Mueller (and others) have advocated in recent years for a global sexual ethic under which all persons have both the right and the responsibility to know their HIV status and to inform their partner of their HIV status (Dixon-Mueller et al. 2009); noticeably absent

in this discourse is a discussion of whether this ethic persists when there are systematic differences in who gets tested within the relationship.

The debate on disclosure has become increasingly relevant since the World Health Organization/Joint United Nations programme on HIV/AIDS revised its guidelines on HIV testing to expand access to testing (WHO/UNAIDS 2007). In countries with generalized epidemics like South Africa, the guidance calls for provider-initiated counseling and HIV testing (PITC) for all individuals attending health facilities, regardless of their reason(s) for initiating care (WHO/UNAIDS 2007). Under this model, individuals will be offered an HIV test and subsequently tested unless they specifically “opt-out” of, or decline, testing.

These newer testing models reflect an effort to reach the substantial portion of HIV-positive individuals who are infected but do not know their status so that they can access lifesaving HIV treatment. Such efforts to reach, test and treat these individuals are especially important in light of recent study findings such as HPTN 052, whereby HIV-positive individuals who initiate treatment earlier are significantly less likely to transmit HIV to their partners than HIV-positive individuals who are not on treatment (Cohen et al. 2011). A global increase in HIV testing rates means that the number of individuals who are faced with the decision to disclose their HIV status to their sexual partner(s) will also increase. Although there is general agreement that increased access to testing is an important goal (Gostin 2006; Gruskin et al. 2008), some human rights advocates have also argued that the “streamlined” consent process that is a part of these new testing models may lead to some individuals unknowingly being tested for HIV or being tested against their will (Gostin 2006; Pierce et al. 2011). Individuals who are tested without consent may be even less prepared to receive – and subsequently disclose – their results than those who willingly test for HIV (Csete and Elliott 2006).

Women are disproportionately affected by PITC guidelines because they come into contact with the health care system more regularly during pregnancy to receive antenatal care (Ahmed et al. 2009; Rennie and Behets 2006). Indeed, South African women are getting tested at greater rates than men, despite the fact that HIV testing is free and available at public health clinics. In a population-based sample from 2008, 28.7% of females between 15–49 and 19% of males reported having an HIV test in the past 12 months (Shisana et al. 2009). The gender gap widens when comparing rates of ever having tested. While 61% of all South Africans have ever been tested, disaggregated figures reveal that 48% of men and 74% of women have ever tested (Government 2010). This unequal rate of testing across gender raises the following questions: if there is a moral obligation to disclose, should this be preceded by a moral obligation to test? Alternatively, if there is no moral obligation to test and the very act of getting tested differs across gender in a setting where the epidemic is driven by heterosexual sex, how might this affect one’s obligation to disclose?

While we acknowledge that there are benefits to HIV disclosure, we believe that labeling disclosure as a “moral” and non-disclosure as “immoral” is problematic on two accounts. First, it is problematic because it places a disproportionate moral burden on women, who in South Africa are one and a half times more likely than men to be tested for HIV. Second, it

is problematic because it unfairly blames individuals with little regard for how the complexities of their relationships shape the process of disclosure.

In this paper, we use the narratives of six HIV+ South African women who have not disclosed their status to their sexual partner to illustrate both the gendered nature of testing in South Africa and how the complexities of their relationships influence their non-disclosure. The systematic differences in testing across gender lines along with women's perceived obligations to their partners help us to see the limitations of adopting a moral framework when discussing HIV disclosure.

Methods

We engaged in qualitative research at an antenatal clinic near Durban, South Africa from July through December 2007 to inform an intervention trial (Maman et al. 2007). We conducted in-depth interviews with six HIV+ women to ask them specifically about non-disclosure of their HIV status to their sexual partner. We recruited these women at a postnatal clinic visit, and women were eligible to participate if they had given birth in the last year, had a sexual partner that they had been with for at least the last six months and had learned their HIV status in their most recent pregnancy. Each woman provided written informed consent. The study was approved by institutional review boards at the University of North Carolina at Chapel Hill and the University of KwaZulu-Natal.

We analyzed our data in multiple steps. First, we read interviews and field notes and created memos of our initial impressions. Second, we used topical codes (e.g. pregnancy intention, description of non-disclosure) to identify patterns in the data. Third, we created a matrix to facilitate comparison across cases (Miles and Huberman 1994), with attention to women's general descriptions of their current relationship and to specific information about the relationship, such as whether HIV testing had been discussed at any point in the relationship. Last, we developed interpretive memos (Saldana 2009) to understand how each case reflected the gendered nature of testing and to understand how the circumstances of each woman's relationship influenced her decision-making around non-disclosure.

Results

The women in our sample ranged from 22–33 years of age and had been in a relationship with their partner between two and six years¹. None of the women were married to their partners but one was living with her partner (and his mother). Four of the women had just given birth to their first child with their current partner. The remaining two women had two children; their first child was from a different relationship. Women's perceived obligation to disclose their HIV status was influenced by their communication with their partner and their beliefs that different life events would change their relationship in ways that would affect the meaning of their HIV infection and thus, their likelihood of disclosing their HIV status.

His desire not to know

Four of the six women had talked about HIV testing with their partner at some point in the relationship, and these women did not feel it was their obligation to disclose to their partners

based on his reaction to these conversations. One woman who talked about HIV testing with her partner was directly threatened by her partner:

Participant: “My baby’s father said if he could get HIV I would be the one to blame but he is the one that used to tell me a lot of things. He used to tell me how much he loved girls...So he usually say if he could test positive he would know that it was all because of me. He says he would kill me.”

Interviewer: “He says he would kill you?”

Participant: “Yes, he says he would kill a person who would infect him with it [HIV].”

Another woman’s partner, while less threatening, also made it clear to her that he had no interest in learning his status even if she did test:

“What he said is if a person feels like testing then they must go and do it alone and keep their results to themselves. Yeah and that was his words, exactly his words. So I cannot go to him and tell him ‘hey it’s like this and that.’”

Finally, while two other participants’ partners did not explicitly state that the women should keep their status to themselves, they were generally unwilling to engage in conversation about HIV testing:

“He said ‘No ways, I don’t think I can stand knowing my status’. I said ‘but why?’ He said ‘what’s with you, why do you keep talking about this?’ I just decided to leave it at that for a time being.”

“I would like him to know my status but I know he won’t accept it because whenever I mention something about it I would notice that he’s not comfortable with it.”

Although the second participant described how she has tried to convince him to go and get tested, she tells the interviewer that she cannot force him to learn his status if he continues not to engage in the conversation and refuses to go and get tested himself.

These four women did not think that their partners had ever been tested for HIV. They also perceived that their partners had little interest in learning their own test results. Based on these conversations, they did not feel it was their obligation to share their HIV status with their partner.

How significant events in the relationship might affect feelings about disclosure

In addition, four of the six participants who had not disclosed described how the meaning of their HIV infection would change with the onset of specific life events. They anticipated that these events would change the meaning of the HIV infection within the relationships and increase their likelihood of disclosure. Two of the women described the importance of learning their infants’ HIV status first:

“It’s best that I tell him after knowing about me and the baby...I have hope that the baby may not be infected.”

These women felt that the child's health would bring security into a relationship that might otherwise be threatened by the disclosure. This was especially the case for one of the participants, who had previously had a miscarriage with her partner.

Two other participants have not disclosed because they no longer feel close to the partners, whom they have been with for two and five years, respectively. Both women described their partners as men who have lied to them and cheated on them. One woman's partner provided no material or emotional support to her or her child and the other supported the child only. In addition, one felt the HIV infection was from her partner. When she found out she was HIV+, she describes herself as follows:

“I was just angry at him. I was very angry; I then told myself that I would not tell him until he goes testing himself. When he returns [from testing] maybe he would tell me or ask me what my results say, then I would tell him.”

Later in the interview, she says that she will not consider disclosing to him unless he proves to her that he is committed to the relationship by initiating the marriage process.

The other participant has no interest in disclosing to her partner given the limited role he plays in her life. She described how she will disclose to him if he becomes critically ill, but not before then:

Participant: “Ummm (thinking) When he reaches a point where he...(changes her thoughts) when he gets critically ill. I would tell him that ‘listen go and have yourself tested’. If he's like...there people who are just stubborn, a person who just keeps on being stubborn over and over again...'let me just tell you what you suffer from' I'll just tell him that you see you have such and such an illness coz I also tested and this is how my results were so it's better if you also go and test...”

Interviewer: “ok...why would you have to wait for him to be critically ill?”

Participant: “You know when he gets critically ill, then it's close to death hey. Yeah, then he would have to understand that this is what he has to do. But then if he totally refuses to go and test, if he doesn't want to know then I would have to tell him that this is the reality...Because it's up to him. Everything is up to him. It's his life. Yes I do realize that we are an item and that we have been together for years but then it's his life, he must be able to take care of it.”

These two women expressed frustration with their partners' behaviour. In response to this frustration, neither had disclosed their HIV status and neither felt that they should disclose at this point in their relationship. They each felt their feelings on disclosure would only change if their relationship were to change in significant ways (through marriage or risk of death). Of the four women who had decided that they would disclose only at a certain point, three stated that they were not currently having sex with their partner and the other woman did not talk about her current sexual behaviour in the interview.

Discussion

There are three clear issues with framing disclosure in moral terms. First, it minimizes our attention to the interpersonal and societal factors that shapes women's communication and behaviour within their sexual partnerships; second, it places undue burden on women who have tested in a setting where there are systematic differences in testing rates; and third, it assumes that disclosure is a single event rather than a process. While some public health officials argue that individuals who know their status are morally obligated to disclose their HIV status to their sexual partners, we are sympathetic to the complexities of our participants' situations and would hesitate to assign moral blame, despite their decision not to disclose.

Framing the discourse on disclosure in moral terms deflects attention away from the interpersonal and societal factors that shape our participants' relationships and their decision-making around disclosure. A number of our participants' decisions were driven by their perceived lack of power within their relationship as reflected in their communication with their partners; for one, this resulted in fear of disclosure-related violence. Research has shown that these fears may not be unfounded: women may face higher risks of violence than men after learning and disclosing their HIV status (WHO/UNAIDS 2007) and general rates of intimate partner violence against South African women are high (Abrahams et al. 2009; Jewkes et al. 2001).

In addition, participants who depended on their partner for economic support worried that the disclosure would drive their partner away; these women felt that loss of such support would have negative ramifications for them and their infant. In our interviews, the support that these women described receiving from their partner was more about "subsistence" than "consumption" (Hunter 2002); that is, women talked about how their partners helped pay their school fees or bought diapers or other goods for their infants. Consistent with other literature on relationships in South Africa, women perceived the material goods their partners provided to be key to their well-being (Dunkle et al. 2004; Hunter 2002; Kaufman and Stavrou 2004). For them, not disclosing protected their access to these goods.

On the other hand, one participant who felt that her partner provided her no material support was ambivalent about her own commitment to her partner. Her non-disclosure was not because she feared negative ramifications from their partnership, but rather was partially attributed to her partner's inability to provide for her and her child, which affected the value she placed on the relationship. Similarly, young women Nthabiseng Motsemme interviewed in the Chesterfield township in KwaZulu Natal felt that their partners were "keepers" as long as they provided for them on some level. These women felt more committed to relationships that offered them support or gifts (or both), and they described how they were less interested in maintaining a relationship when their partner was unable to fulfill this part of his role (Motsemme 2007).

Nonetheless, most of our participants talked about not disclosing at least in part because they had little power to control the outcomes of disclosure and they needed their partner's support. It is unclear whether the societal protections in place for HIV+ South African

women who experience negative outcomes after disclosure are sufficient to meet the needs of the ever increasing number of women learning their HIV status (Rennie and Behets 2006). Though O’Leary and Wolitski acknowledge that power dynamics within a relationship might affect a woman’s ability to live up to her “moral standards” to engage in responsible behaviour (O’Leary and Wolitski 2009), they do not discuss how to reconcile this with their call for the development of interventions to discourage “moral disengagement.”

A majority of our participants had discussed HIV and testing earlier in their relationship with their partners. In these conversations, women received explicit messages that their partners were not interested in knowing their HIV status. Further, through these conversations, the partners made it clear that HIV was not a topic that they wanted to discuss within their relationship; similarly, South Africans in other qualitative studies preferred to discuss HIV indirectly or in veiled or impersonal ways (Lambert and Wood 2005; Mindry et al. 2011; Motsemme 2007).

Some of our participant’s partners told their partners that they would interpret an HIV diagnosis as a sign of sexual infidelity, regardless of the actual origin of the infection. It may be that women in our study did not disclose in accordance with one cultural script on infidelity, whereby there is an expectation that many individuals engage in multiple concurrent partnerships, but that they are not openly discussed or openly engaged in (Leclerc-Madlala 2009; Motsemme 2007). According to this script, “respect” for a partner is manifest when each individual is committed to upholding the other’s social reputation. That is, while there is not necessarily an expectation that one’s partner will not engage in concurrent relationships, there is an expectation and shared understanding that each individual will “not in some way disgrace the other partner” (pg. 4, Leclerc-Madlala 2009) when doing so. While the literature to date has focused on how important discretion and respect are when one or both individuals in the partnership are negotiating multiple relationships, similar expectations may be applicable to communication around sexual health as well.

Once our participants received their HIV+ diagnosis within the context of their pregnancy, they were then faced with the decision as to whether they would explicitly ignore their partner’s wishes and disclose their status, or whether they would respect the established parameters of communication on the topic as set by their partner. Future research on the role of gender in communication between partners about sexual health will help us to better understand whether women who do not disclose after previously discussing HIV with their partners are doing so to conform to an expected role within the relationship or whether they are using these conversations to excuse themselves from a potentially difficult conversation.

Nonetheless, assigning moral blame to individuals who do not disclose their HIV status may disproportionately marginalize women. National rates of testing reveal that South African women are tested for HIV at significantly greater rates than men. Four of the six women in our study had talked about HIV testing with their partner; none of the six knew their partner’s HIV status. When there are systematic differences in who gets tested for HIV, the use of moral language to promote disclosure may unduly burden the population who is

tested. In this case, the use of moral language places the burden of disclosure at an individual level. This might be fair in a setting where all individuals share the burden of getting tested for HIV equally. However, in the South African context, prevention discourse centered on individual's moral obligation to disclose disproportionately affects women.

Finally, when we label disclosure as moral, we fail to recognize that disclosure is a process. Women in our study anticipated that their perceived obligation to disclose might change with the occurrence of significant events in their family or relationship. For example, women described waiting to confirm the good health of their child as an important precursor to being able to discuss their HIV status with their partner. Similarly, women participating in qualitative research in Vlundela (a rural area outside of Pietermaritzberg) and Soweto (a township outside of Johannesburg) described how they framed conversations about HIV risk with their partner by linking the topic directly to their children's health and future (Mindry et al. 2011). Other women in our study talked about how a partner's gesture (such as the initiation of lobolla payments) would show that he was committed to the partnership. Such gestures were imagined to be great value, particularly given the high cost and low rates of marriage in this setting (Hunter 2007). Our participants suggested that these life events would have bearing on the meaning of their HIV infection for the relationship and their subsequent sharing of their status. Future longitudinal research would help us to better understand our participant's processes of disclosure and specifically, how their perceived obligations do or do not change over time in conjunction with different life events.

Others have described the way in which one's experience of their HIV infection has changed the meaning of disclosure over the course of their relationship with their sexual partner (Leonard and Ellen 2008). Similarly, Johnny Steinberg, a South African journalist, wrote an entire book about the life of one young South African man named Sizwe and his process of deciding not to get tested for HIV (Steinberg 2008). These ethnographies of disclosure and HIV testing are similar in their complexity with our participants' lives. Each reminds us that the disclosure may not occur as a single incident, but rather one that changes in response to significant life events in both the sexual relationship and an individual's broader environment. There is no acknowledgement of the process of disclosure in discourse that calls for a sexual ethic in which there is an obligation to disclose. The utility of such discourse may be limited when seeking to develop interventions that help individuals make meaning of how their HIV diagnosis will affect not only their own lives over time, but also the lives around them.

Conclusion

Given the ever increasing number of individuals learning their HIV+ status, there is a need to move beyond a focus on "moral disengagement" to identify interventions which support pregnant women in committed partnerships through the disclosure process. There are currently three different public health approaches to facilitate HIV disclosure; individual counseling sessions to assist individuals with self disclosure, couples-counseling (wherein HIV testing and disclosure occur simultaneously) and provider-initiated partner notification programs. Individual counseling sessions have been shown to be effective at increasing partner referral for other STIs in Zimbabwe (Moyo et al. 2002), however there is little

research that assesses how individual HIV counseling assists women specifically with the disclosure process during and shortly after pregnancy. In particular, we do not know how best to support women who learn that they are HIV+ during pregnancy, particularly if they are in inequitable relationships or have limited access to social support.

Couples-counseling as part of antenatal care has also been understudied. Two early observational studies in Kenya and Zimbabwe (prior to the availability of ARVs other than Nevirapine) appeared to have beneficial health outcomes (uptake of HIV testing, increased uptake of Nevirapine, adherence to breastfeeding recommendations), however, less than 15% of women's partners participated in either setting (Farquhar et al. 2004; Semrau et al. 2005). It is clear that additional research is needed to understand the barriers to couples-counseling in the context of antenatal care, particularly now that ARVs are more widely available.

Finally, while there is little research on provider-initiated partner notification programs in developing countries, a review of provider-initiated partner notification programs in the U.S. revealed that a majority of patients thought they were an acceptable mode of contacting individuals who had been exposed to HIV (Passin et al. 2006). The primary barriers to participation in such programs included concerns about client confidentiality and fears of negative outcomes, both of which may be of substantive concern for pregnant South African women. Research regarding the acceptability and feasibility of partner notifications programs would be necessary prior to implementation in the antenatal context.

Although HIV testing is becoming increasingly accessible, the gap in how to best support disclosure in sub-Saharan Africa persists. Each of these intervention strategies should be more seriously considered and evaluated as potential alternatives through which the weight of disclosure does not reside entirely on the shoulders of women who access antenatal care. In addition, there is still a pressing need for interventions that facilitate uptake of HIV testing and counseling among men.

While labeling disclosure may not serve its intended purpose, disclosure at its best can confer health benefits to the individual and to the public at large. When one individual discloses to another and they subsequently engage in safer sex, then disclosure reduces transmission of HIV from one individual to the next. An additional often overlooked benefit is that disclosure can lead to social support for the HIV+ individual (Kalichman et al. 2003; Smith et al. 2008; Visser et al. 2008). Yet disclosure is a complicated process and the public health community should be wary of language around morality as a means to increase uptake of the practice. Rather, we should continue to engage in research that seeks to understand the complexities of sexual partnerships in different contexts. Such understanding may ultimately help us to devise public health interventions on HIV status disclosure that better recognize and respond to the myriad influences on human behaviour.

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