



Published in final edited form as:

AIDS Behav. 2014 January ; 18(0 1): . doi:10.1007/s10461-013-0521-1.

Double Disclosure Bind: Complexities of communicating an HIV diagnosis in the context of unintended pregnancy in Durban, South Africa

Tamaryn L Crankshaw^{1,2}, Anna Voce¹, Rachel L King^{3,4}, Janet Giddy², Nicolas M Sheon⁵, and Lisa M Butler^{3,6}

¹Department of Public Health Medicine, University of KwaZulu-Natal, Durban, South Africa

²McCord Hospital, Durban, South Africa

³Global Health Sciences, University of California San Francisco, San Francisco, United States

⁴Karolinska Institute, Dept of Public Health, Division of International Health, Stockholm Sweden

⁵Center for AIDS Prevention Studies, University of California San Francisco, San Francisco, United States

⁶Department of Epidemiology and Biostatistics, University of California San Francisco, San Francisco, United States

Keywords

PMTCT; HIV Disclosure; unintended pregnancy; South Africa

Introduction

Disclosure of HIV status to sexual partners and significant others has been recognized as essential to the modification of sexual behavior and the management of HIV (1, 2). In addition, communicating HIV diagnosis to significant others is viewed as an important step in securing support, which has been shown to positively influence the overall health, quality of life, and treatment adherence of HIV-positive individuals (3–5). Rooted in the historical voluntary counseling and HIV testing (VCT) context, the prevailing disclosure model is based on a medical model of prevention which assumes that some form of verbal negotiation between partners, including communication about past risks, takes place before embarking on a sexual relationship (6–8). However, disclosure of HIV status is mediated by a host of factors, including an individual's psychological state, her/his communication skills, the individual's relationship with the intended disclosure recipient, and the fear of being stigmatized by others (9–15).

Effective interventions for the prevention of mother-to-child transmission (PMTCT) are an ongoing priority in South Africa, where the national antenatal HIV prevalence is 29.5% (16). In this context, HIV disclosure is generally recommended by PMTCT health providers and counselors as a means to support safer sexual behaviors to reduce the probability of HIV transmission to sexual partner(s), as a way to access social support to promote antiretroviral treatment adherence, and as a method to garner partner and/or family support for exclusive breastfeeding. Recent data indicate that nondisclosure of HIV status is strongly associated

with nonoptimal PMTCT outcomes and increased risk of mother-to-child HIV transmission (17, 18).

The current HIV-disclosure counseling paradigm, however, is not consistent with the reality of many women's lives in South Africa, as it largely assumes that women are in stable monogamous relationships, have access to birth control, plan their pregnancies, and have reliable access to food and shelter. In fact, many women are likely to discover their HIV status before their sexual partners as a result of antenatal clinic attendance (19, 20), and are therefore burdened with the responsibility of disclosing their HIV-positive status and/or pregnancy to partners who might respond negatively. The 1998 South African Demographic Health Survey, in which 11,735 women were interviewed in all the country's provinces, found that 61% of all first pregnancies and 46% of all second pregnancies were unintended* (21). A study among 242 antenatal attendees in the KwaZulu-Natal province found that 84% of all pregnancies were unintended (22). Prior research has shown that pregnant women, as a general population, are especially vulnerable to experiencing violence (23, 24), and HIV-positive women, in particular, are more likely to report lifetime violence than HIV-negative women (25). Following disclosure, HIV-positive women have also been found to experience breakdown or dissolution of a relationship (3, 26), economic abandonment, rejection, and isolation (3, 14, 27–29). Prevailing assumptions that an HIV-positive pregnant woman will prioritize her own, her partner's, and her infant's health once made aware of her status do not allow for the possibility that this may be subordinated to more immediate and basic needs.

We conducted a qualitative study to investigate HIV-disclosure dynamics among HIV-positive pregnant women accessing PMTCT services in an urban area with high HIV prevalence. This study will inform a broader theoretical position that well-informed counseling and support is required for HIV-positive pregnant women in a clinical context, in order to achieve better maternal mental-health and, by extension, child-health outcomes.

Methods

The study was conducted between June and November 2008 in two antenatal clinics providing PMTCT services within the eThekweni district in KwaZulu-Natal, South Africa. One site was a public-sector community health clinic (39% antenatal HIV prevalence) and the second site was a state-subsidized district hospital (16% antenatal HIV prevalence). Both sites served populations living in urban and peri-urban areas, with PMTCT services offered at no cost to those who accessed antenatal care (approximately 35 USD per consultation at hospital site; no charge at public-sector site).

We consecutively recruited, enrolled, and conducted semi-structured interviews at both clinics with women seeking PMTCT services who were aged 18 years, HIV positive, pregnant, and black African. The interviews were conducted in isiZulu by a black female South African interviewer who had prior training and experience in qualitative and ethnographic research methods and did not work at either study clinic. The interview guide consisted of open-ended questions on the effects of HIV diagnosis on women's lives, relationships, and pregnancies and on women's decisions, experiences, and outcomes during the HIV-disclosure process. All interviews were audio recorded.

Interview data were transcribed and translated into English. Drawing on grounded theory methods, transcripts were read multiple times to allow the researcher to become familiar

*Due to data-quality issues with the fertility section of the 2003 SADHS, the 1998 survey figures are reported. However, the 2003 SADHS reported unintended pregnancy trends similar to those of the 1998 SADHS.

with the data and then identify codes. Emergent themes and subthemes were inductively derived through the coding process as laid out by Corbin and Strauss (30). These data-driven themes serve as findings, and they inform our interpretation of the relationships among our categories.

Ethics approval was granted by the Biomedical Research Ethics Committee at University of KwaZulu-Natal and by the hospital's Research Ethics Committee. Written informed consent was obtained from all study participants.

Results

Participant Characteristics

Of the 63 women who were asked to participate, 62 (98%) consented—31 from each of the two sites (median age = 26 years, IQR = 22–29 years). Most participants were single ($n = 55$; 89%) and fewer than one-third ($n = 17$; 27%) lived with their partners on a regular basis. Seven women (11%) reported that they were currently separated from the father of their child. Thirty-nine women (63%) had been diagnosed with HIV within the previous year, and 37 (95%) of these women were diagnosed by routine HIV testing during pregnancy. The majority of women ($n = 42$; 68%) reported that their pregnancy was unplanned. Overall, 37 women (60%) had experienced both an unintended pregnancy and a recent HIV-positive diagnosis (< 1 year).

Themes

1. Internalized stigma related to HIV-positive diagnosis—An HIV diagnosis, without pregnancy considerations, was deeply upsetting for many women. Some participants touched on the emotionally painful concept that they had brought HIV upon themselves because of previous, perceived “bad” behavior, and therefore they feared disclosing to others. Many women expressed anger at having acquired HIV. This anger was directed either at themselves or at a partner who was viewed as the source of HIV infection.

“I was very angry with my partner [when I tested positive] because I knew I hadn't cheated on him. I asked him what he did in my absence. I was very angry, and I shouted at him. I told him I was negative when I tested with my first child. Now I am positive. I blamed him for it.” (25-year-old woman)

Deep sense of personal failure emerged as a recurring theme.

“[To be HIV positive] means I am empty. I am ‘fucked up’. I mean that my life is empty. What else can I do when I am HIV positive?” (26-year-old woman)

“At times I see myself as a failure and ask myself, “Why me?” ... I keep blaming myself. I was careless. My mother used to talk to me about everything, and she made it a point that I was protected from this disease. She said she wanted me to have a life she didn't even have, and I disappointed her. So I think of myself as a dismal failure.” (27-year-old woman)

Stigma was cited as the main reason women delayed disclosure, sometimes for years:

“... it has taken me a very long time to accept that I am living with this disease. It took me years.” (27-year-old woman)

“HIV is not like other diseases. It is a shameful disease, and when you tell other people about your status, they judge you as someone who has been sleeping around. I wish I didn't have this virus. It is not easy to disclose something that everybody would not like to have, something that everybody is talking badly about. ... I just don't see myself telling anyone, and I will not.” (30-year-old woman)

2. Impact of unintended pregnancies on women's lives and relationships—

Because most of the pregnancies were unexpected, participants were trying to assimilate their feelings about being pregnant, which often were not directly linked to their HIV status.

“I am still trying to deal with my emotions right now. To tell you the truth, I can't tell you how I feel right now. ... Well, I have made peace with the HIV. I am specifically talking about the pregnancy because, I mean, it wasn't planned, you know.” (28-year-old woman)

An unanticipated pregnancy caused considerable disruption to participants' lives, resulting in some women dropping out of school or resigning from jobs. This had a direct effect on how they responded to their pregnancy, with many expressing dismay. Women in this social context are primarily responsible for supporting and raising an unplanned child, with or without financial or emotional commitment from the father. A 22-year-old student shared her profound dismay about a second pregnancy and its effect on her academic future:

“This child I am carrying is a big mistake. I don't know how it happened, because I was on a pill. ... I don't know what I should do now, because when I asked for an abortion, the nurses said it was too late. I want to ask the nurses today what happens if a mother does not want the child. My partner said he wants nothing to do with this pregnancy. As it is, I asked him to buy some clothes for the child and he refused. ... My grandmother said if I get pregnant again, she won't pay for my education.”

The announcement of an unplanned pregnancy was often unwelcome news for the participants' family members, with grandmothers frequently taking primary responsibility for child care. In addition to her own feelings of shock, a young woman (who had not disclosed her HIV status) recounted how her mother reacted when informed of the pregnancy:

“Eish, she shouted at me. She was only short of beating me up. She said I had disappointed her. She cried a lot.” (18-year-old woman)

A 36-year-old employed woman did not want to have a baby for other reasons:

“Naturally I don't like children ... I think it is because we grew up watching our father having relationships with women who already had kids. He would fall in love with a woman and bring her, together with her children, to our house. On top of that he would make this woman pregnant, and he would love this woman's children more than us.”

Pregnancy also had an impact on sexual relationships. For some it was negative: 10 percent of the pregnant participants were no longer in a relationship with the father of the child. Although the reasons were multifactorial, in some cases it was a direct consequence of the pregnancy. A 31-year-old employed woman had been in a relationship for three and a half years, which ended the day she informed her partner of her pregnancy. He reportedly asked her to terminate the pregnancy. When she refused, he informed her via email the next day that the relationship was over.

Preexisting gender power imbalances were exacerbated by the women's inherent material vulnerability during pregnancy, a time when their partners held much of the bargaining power. A 30-year-old unemployed woman believed that her partner had infected her, yet she was passive in determining the future of their relationship. Her passivity was strongly influenced by an awareness of her vulnerability: being pregnant with no income of her own to support herself or her child.

“It came to my mind when we tested positive that he might leave me, but when we talked about it and he said we must continue our relationship, I was relieved. ... It would be very difficult for me [if he left the relationship] because I was pregnant and unemployed. It would mean I would have to raise my child single-handedly. It is not a good thing to be dumped with a child.”

While pregnancy caused some relationships to disintegrate, for other women, it was reason for greater commitment from their partners. Even though one woman’s partner was already married, he continued to support her after she announced her pregnancy.

“At the moment, everything is fine. I always think getting pregnant by him was a blessing because he gives me support. He gives me that support because I am pregnant and it is his child.” (36-year-old woman)

3. Interplay of pregnancy and HIV diagnosis—Two-thirds (60%) of the participants were diagnosed with HIV in the last year, as antenatal patients. One woman reported that if it were not for her pregnancy, she might have avoided being tested for HIV.

“I was only compelled to do it when I was pregnant. ... I am not sure if I would [have tested if I was not pregnant]. I don’t think I would. At times it is difficult to face reality. You feel better if you keep it in suspense.” (29-year-old woman)

Because their pregnancy and HIV diagnosis were concurrent, the women had little time to adjust to the impact on their life as well as on their unborn child.

“What made it worse was that I first discovered that I was pregnant and then, later, HIV positive. It was like putting salt in an open wound.” (21-year-old woman)

“I was confused. There were so many things happening at the same time. ... Like testing positive and getting pregnant. Everything was just overwhelming ...” (28-year-old woman)

Making peace with their feelings of personal responsibility for risk behaviors that led to HIV diagnosis was difficult for some women. A 21-year-old student was trying to come to terms with her one reported unprotected sexual encounter, which resulted in both HIV acquisition and pregnancy.

“I think, though, acceptance is the best way to deal with HIV. Not accepting your status will only make matters worse. I only had sex with this guy once, and we didn’t use a condom. I had never had sex before that. I never thought anything could happen. It was the first time, and I got pregnant, and I got HIV as well. Whenever I think of that day, I feel angry with myself, because I am to blame. I can’t go around blaming other people when I am the one that put myself in all this trouble.”

4. Impact of pregnancy on HIV-disclosure decision making—Pregnancy affected HIV-related disclosure in a number of key ways. Most participants feared that their partners or parents would abandon them if they disclosed their HIV-positive diagnosis. A 34-year-old employed woman was engaged to marry her partner yet was withholding her HIV status. Although she recognized that this could be seen as a betrayal, she decided to wait until the baby was born before telling him.

“I am not ready to tell him because, since I am pregnant, anything can happen [to the child or myself]. What I told myself was that I have to put this baby first, for now, and then deal with the other things afterwards.”

A 25-year-old employed woman reported that she would wait for the result of the baby's HIV test before she disclosed to her mother, in order to spare her mother from any worry over the child's health. A 22-year-old unemployed woman withheld her HIV diagnosis from her partner so as not to compromise his excitement over the pregnancy. She decided not to tell her mother for fear of becoming a double "disappointment":

"... I have been a bad girl by falling pregnant, and now to tell her I am HIV positive, it will be too much for her."

Varying levels of HIV disclosure were evident within the pregnancy dynamic. A 21-year-old employed woman had disclosed her HIV status to her partner, but was cautious of telling him about the potential risk to the child.

"I haven't told my partner about the chances of the child being infected. ... I think he will be very worried. I won't tell him about this."

HIV disclosure was often subordinated to the more immediate concerns around announcing the pregnancy, which include the customary practice of the baby's father presenting himself formally to the woman's family and arranging to pay "damages" (*inhlawulo*) in order to claim custody of a child born out of wedlock. A 20-year-old woman described a double disclosure bind surrounding the stigmas of unplanned pregnancy and HIV infection.

"You see, the problem is where I come from. I come from a very traditional community. Even this pregnancy will be a big issue when I go back home, because I will be expected to introduce my boyfriend to my parents, and the whole community should be invited to come and see him. So since I am pregnant, I haven't told anybody except my mother. It would be even worse to tell them I am HIV positive."

The complexities of unintended pregnancy and HIV diagnosis were not the only considerations for some participants during their disclosure decision-making process. One woman felt that she could not tell her family about her HIV status because they did not endorse her relationship with her partner and they already viewed her pregnancy as a disgrace.

"Nobody knows at home. At the moment, it is me and my partner that are aware that I am HIV positive. I really don't feel I can tell them at the moment. ... The reason for that is that they were not in favor of me having a relationship with my boyfriend. I had spent a very long time after I separated with my previous boyfriend. So when I eventually found myself a boyfriend, I quickly got pregnant. So it would be a disaster for them to hear that I am now HIV positive." (36-year-old woman)

Discussion

The themes identified above reveal that an HIV-positive diagnosis led many women to take stock of their lives and often marked the beginning of a fundamental shift in their self-identity. Many were deeply shocked or angered by their diagnosis, and while some felt that they had not paid enough attention to HIV prevention, many had been exposed to risk outside of their control. In the antenatal context, HIV-positive pregnant women must deal simultaneously with two important implications of their HIV diagnosis: the risk of transmission to their partner and the risk posed to their unborn child (9). Given the high rates of unintended pregnancy in South Africa (22, 31–33), many women who get tested positive for HIV the first time are also experiencing an unanticipated pregnancy. HIV diagnosis is also likely to occur late in a pregnancy, because women in South Africa typically attend their first antenatal visit during the latter part of the second trimester (34, 35). Women fitting

this profile are a high-risk population in terms of vertical and horizontal HIV transmission. Nondisclosure tends to be more frequent among women diagnosed with HIV late in pregnancy, and nondisclosure has been linked with increased rates of mother-to-child transmission (17, 18). For women experiencing unintended pregnancies, dual disclosure needs to be negotiated: communication of pregnancy and communication of HIV infection. Disclosure of HIV poses a potential threat to relationships because it involves communication of direct risk to the partner and it calls into question the risk to the baby (9).

Prior research has shown that, among women, unmarried status and economic vulnerability are significantly associated with nondisclosure of HIV status (17). Given that most of the study participants were unmarried, it is perhaps unsurprising that HIV concerns were often subordinated to pregnancy concerns when the need to maintain a relationship during pregnancy outweighed the need to communicate to a partner's own risk. In research conducted in Cote d'Ivoire, women reported extended postpartum abstinence from sex as a strategy to avoid the risk of transmission to partners to whom they had not disclosed (9). In a later, related study, investigators found that women who did not routinely cohabit with their male partner were less likely to communicate with him about sexual risk behavior, whatever their HIV status (19). In our study, some women wanted to first ascertain that their infants were HIV negative before they revealed their own status. This may have been due to their very immediate anxieties over the well-being of their infant and/or a strategy to mediate the shock to the father when disclosure did occur. Current disclosure approaches in the PMTCT clinical setting, however, reflect little awareness of the double disclosure bind in which such women find themselves.

The study findings underscore the far-reaching personal, social, and economic consequences for women who have unintended pregnancies. In many South African communities, pregnancy is considered shameful if the father has not been formally introduced to the mother's family and paid *inhlawulo*. Some participants revealed that their partners were reluctant to admit paternity and had subsequently ended the relationship. This finding is consistent with other local research and appears, in part, to be related to the payment of *inhlawulo* (36).

The stress and sudden complexity of her diagnosed conditions can have a significant impact on a woman's mental health, which can be detrimental to her and her infant's well-being (37, 38). Recent research points to the presence of post-traumatic stress disorder in HIV-positive individuals as a result of their exposure to various related events, including HIV diagnosis and treatment and HIV disclosure (39). Additionally, HIV-positive women experiencing unintended pregnancy have been found to be at high risk for antenatal depression (22). These women have vulnerabilities unique to those of an adult woman who is not pregnant. HIV diagnosis for a pregnant woman has ramifications not only for her health but also for her unborn child and any sexual partner on whom she is financially dependent, and it has a ripple effect throughout her wider social network.

Implications for Counseling in the PMTCT Setting

Our findings, that the double disclosure bind resulted in HIV disclosure being subordinated to concerns over the maintenance of relationships and continued social support, suggest that counseling and disclosure decision making should receive closer attention within prevailing PMTCT models. When an HIV-positive diagnosis is concurrent with an unintended and late-term pregnancy, it is reasonable to delay messaging that emphasizes immediate HIV disclosure, in order to support the woman during a time of extreme psychological and social vulnerability. Providers must allow for the possibility that some clients may require time to come to terms with the initial shock of their HIV diagnosis before they can share their status with a significant other.

Dealing with these psychosocial and relationship-power nuances may not be comfortable for health care professionals, who are pulled between their ethical obligations of patient confidentiality and preventing harm. But in the absence of clear guidelines for South African health care providers regarding HIV disclosure, an understanding of the structural and contextual issues is useful. It is vital for providers to consider the sociocultural and health care contexts in which disclosure is encouraged, as this will influence the likelihood of disclosure and the achievement of desired outcomes (40). In addition, an individual's relationship to the intended disclosure recipient is a key factor in the process (9–15). For example, Marks and Crepaz (41) found that disclosure did not necessarily reduce unsafe sex, and of those who did not disclose, 73% actually engaged in safer sex.

Future research should explore counseling strategies that acknowledge the personal and cultural contexts of disclosure. Couple's counseling and testing, for example, could provide a context in which issues can be addressed more safely. Another support mechanism is to enlist a counselor or friend for "assisted disclosure" (4). In this way, social support can provide a backdrop for the disclosure event, and responsibility will not rest solely on the shoulders of the woman receiving antenatal care.

Acknowledgments

This study and the lead author (TLC) received support through the Centre of HIV/AIDS Networking (HIVAN), University of KwaZulu-Natal from the National Institute of Child Health and Human Development (NICHD), Partnership for HIV/AIDS Research in South Africa (R24 HD43554) and Atlantic Philanthropies. The lead author (TLC) also received support from the University of California, San Francisco from the following grants from the U.S. National Institutes of Health (NIH): National Institute of Mental Health (NIMH), Center for AIDS Prevention Studies (P30 MH062246), International Traineeships in AIDS Prevention Studies (ITAPS, R25MH064712), and the Fogarty International Center (FIC) AIDS International Training and Research Program (AITRP, D43TW000003). The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH, NICHD, NIMH, FIC or Atlantic Philanthropies. We would like to thank Sbonile Maimane from the Centre for HIV/AIDS Networking (HIVAN) for conducting the interviews and Lynae Darbes and Angelica Espinosa Barbosa Miranda for their review of this paper and their thoughtful comments. We are especially grateful to all the women who participated in the study and so generously gave of their time and perspectives.

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