To tell or not to tell: South African women's disclosure of HIV status during pregnancy

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Abstract

HIV-positive pregnant women often do not disclose their serostatus to their partners, family and friends, creating potential barriers to preventing sexual transmission to partners and mother-to-child transmission through breastfeeding. This research explores recently diagnosed HIV-positive pregnant women's reasons for disclosure and non-disclosure of serostatus to various members of their social networks, as well as the consequences of their disclosure. Data were collected through open-ended questions as part of a semi-structured interview with 293 recently diagnosed HIV-positive pregnant women recruited from antenatal clinics in two townships in Tshwane, South Africa. A content analysis of responses showed that women weighed fear of abandonment and discrimination against their desire to raise risk awareness and their need for support. Partners most often responded to disclosure with disbelief and shock, whereas parents frequently exhibited emotional distress, but were still supportive, as were other relatives and friends. The women subsequently experienced low levels of adverse consequences after disclosure. The results can assist healthcare providers in understanding the complexity of pregnant women's decisions to disclose to various members of their social networks and emphasize the need for continued counselling and support.

Keywords: disclosure; pregnant women; qualitative research; HIV+ women in Africa

Introduction

It is well known that individuals diagnosed with HIV often have difficulty disclosing their status to others. This is particularly relevant for women in developing countries such as South Africa (Gebrekristos, Abdool Karim, & Lurie, 2003; Olley, Seedat, & Stein,2004; Sethosa & Peltzer, 2005) where they are often economically, culturally and socially disadvantaged and may fear abuse or abandonment once their diagnosis is known (Mokhoka, 2000; Skinner & Mfecane, 2004). As a result of efforts to decrease perinatal HIV transmission (World Health Organization, 2004), increasing numbers of pregnant women discover that they are HIV-positive during pregnancy. This can be particularly

traumatic for a woman because in anticipating the birth of her child, she has little time to deal with her diagnosis. Yet hiding her diagnosis can have serious implications regarding the risk of HIV transmission to her child at the time of birth and through breastfeeding. Indeed, in a study done in Kenya, women who had disclosed to their partners were more likely to bottle-feed than those who had not disclosed (Farquar et al., 2001).

Disclosure of HIV status involves a process of decision-making, based upon numerous factors, including psychological state, communication skills, motivation and anticipated reactions. The stages of disclosure involve: coming to terms with the traumatic diagnosis; deciding upon the appropriateness of disclosure to a specific person, weighing the anticipated consequences and benefits of disclosure; and then choosing an appropriate situation for disclosure (Kimberly & Serovich, 1996). This process, well described in the HIV/AIDS literature, has not been given appropriate attention for HIV-positive pregnant women who face particularly challenging choices (Doull et al., 2006). Personal reasons for disclosure include stress relief and access to social support and treatment. On an interpersonal level, disclosure is motivated by an effort to maintain honesty in relationships and to protect others from infection or to encourage behaviour change (Kalichman, DiMarco, Austin, Luke, & DiFronzo, 2003; Simoni et al., 1995). In contrast though, in a study of women who tested HIV-positive during pregnancy, the primary reason given for disclosure was to avoid transmission through breastfeeding and to obtain care for the infants (Varga, Sherman, & Jones, 2006).

A number of researchers have examined reasons why people do not disclose their status although these are not studies specifically of pregnant women. Medley et al., (2004) identified the following barriers among women in developing countries: fear of accusations of infidelity, abandonment, rejection, discrimination and violence, disruption of family relationships, emotional and physical abuse and, most of all, fear of loss of economic support from a partner. Clearly, these barriers stem from an awareness of stigma associated with HIV/AIDS (Bond, Chase, & Aggleton, 2002; Simbayi et al., 2007; Skinner & Mfecane, 2004; UNAIDS, 2004). However, women in long-term and trusting relationships found it easier to disclose to their partners (Maman et al., 2001) and to family and friends who are likely to offer support (Kalichman et al., 2003).

African research shows that while fears of disclosure are legitimate, consequences are often less severe than anticipated. Medley et al.'s review of disclosure (2004) found that while 4-28% of women reported negative consequences of disclosure, such as blame, violence, abandonment and stigma, many respondents (19-73%) reported positive outcomes such as kindness, understanding and acceptance after disclosure. In a South African study, only 12% of disclosures resulted in less kindness; 70% in no change in the relationship and 19% in an increase in kindness (Kuhn et al., 1999). The adverse effects due to disclosure included violence from their sexual partners (13%), loss of a partner (9%) and abandonment from home (3%). For pregnant women in South Africa, voluntary disclosure ultimately resulted in a supportive, constructive response (74.2%), after some partners' (27%) initial upset, anger or rejection (Varga et al., 2006). Clearly women must weigh the likelihood of an expected negative reaction with the possibility for a positive outcome when considering to whom to disclose.

To bolster the limited research on disclosure of HIV-status during pregnancy, we seek to identify why South African women who test HIV-positive during pregnancy disclose to some individuals in their social networks yet not to others, and what experiences result from these disclosures. In this study we have used qualitative responses obtained from women at the time of enrolment in the Serithi Project1 to provide a greater understanding of the issues surrounding disclosure following an HIV diagnosis during pregnancy. Increased understanding of the barriers and consequences of disclosure in pregnancy could contribute to improving counselling and support of women diagnosed as HIV-positive in pregnancy.

Methods

Participants

Study participants were recruited from four antenatal clinics serving two large communities in Tshwane, South Africa. The clinics provide health services and HIV testing to a mainly black, low to middle socio-economic class, urban population. HIV counselors from the clinics referred women recently diagnosed during pregnancy to the study and 317 women agreed to participate by giving informed consent. Twenty-four individuals were excluded from the current sample because they had tested positive prior to pregnancy, leaving a sample size of 293.

Data collection

Women were interviewed during pregnancy (mean gestational age of 28 weeks) shortly after finding out that they were HIV-positive. Trained research assistants conducted semi-structured interviews in the participants' mother tongue: IsiZulu, Tswana or Sepedi. This report uses the following data obtained from open-ended questions included in the interview:

1. Whether or not participants had disclosed their HIV-status.
2. To whom they had disclosed, reasons for disclosure to that person(s) and reactions of the person(s).
3. Reasons for non-disclosure to others in their social network (specifically, participants were asked about partners, parents, in-laws, other family, friends and other members of their community).
4. Adverse consequences as a result of being HIV-positive (11 possible consequences were presented to the respondents).

Data analysis

Content analyses (Stemler, 2002) were performed to categorize and code reasons for disclosure and non-disclosure to various members of the women's social networks and reactions to disclosure. Two independent researchers interpreted the data and whenever there were discrepancies, developed consensus after discussion.

The study was approved by the Ethics Committee of the Faculty of Health Sciences of the University of Pretoria and the Human Investigation Committee of the Yale University School of Medicine.

Results

Characteristics of study participants

At the time of the interview, 80% of the women had known their HIV status for less than four weeks (median 1 week). Participants were aged between 17 and 41 years, with an average age of 26.5 years. While 88.7% of the women indicated that they had a partner (20.5% were married and 68.2% not married), 42.1% were not living with a partner and 11.3% did not have a partner at the time of the interview (the partner had left or the woman did not have a relationship with the father of her baby). They were mainly from low socio-economic status with an average monthly household income of about US$66. Eleven percent had primary school education or less and 71.3% had at least some secondary level education.

Disclosure

Of these women, 59% had disclosed their HIV status to at least one person other than healthcare providers, while 41% had not done so. Forty-one percent of the women had disclosed to only one person, 11.3% had disclosed to two people and 7.2% to three or more people. Those who had disclosed had primarily told their partners (80% of those who had partners), their parents (20.2%) and other family members (23.1%). Few respondents disclosed their status to others outside of their immediate family (14.6%).

Reasons for disclosure

The women provided diverse reasons for disclosing their HIV status to their partners, parents, other relatives and friends (See Table 1). The most common reason given for disclosing to partners was to inform them of the risk of infection, to encourage testing and change risk behaviors (31.7%). Of the women who disclosed, 30% did so because of a sense of responsibility or obligation because of the relationship. Of these women, 13 (9%) felt obliged to tell their partner because he was the father of their unborn baby. The following are examples of women's responses: “I told him to inform him that we are both HIV-positive and that we need to change our lifestyles” and “He has the right to know as the father of the expected child. I had the responsibility to disclose.”

A small number of women (4.8%) disclosed to prepare their partners for a potentially HIV-positive baby or to obtain support from a partner in preventing transmission to the infant.

Table 1. Reasons for disclosure to members of social network.				
Reasons for disclosure*	**Partner (*n*=145) *n* (%)**	**Parents/caregiver (*n*=40) *n* (%)**	**Other relatives (*n*=49) *n* (%)**	**Friends (*n*=35) *n* (%)**
Notes: *Total *n* is greater than sample size, as some respondents provided more than one reason for disclosure and disclosed to multiple individuals				
Raise risk awareness	46 (31.7)	0	2 (4.1)	1 (2.9)
Responsibility/obligation given the relationship	43 (29.7)	8 (20.0)	2 (4.1)	0
Supportive/trusting relationship	19 (13.1)	21 (52.5)	29 (59.2)	29 (82.9)
Tested together/discussed HIV previously	13 (9.0)	0	3 (6.1)	2 (5.7)
Prepare for HIV-positive baby, protect/support child	7 (4.8)	2 (5.0)	1 (2)	0
Legacy/explanation of behaviour, illness and death	3 (2.1)	6 (15.0)	5 (10.2)	0
Other	14 (9.7)	3 (7.5)	7 (14.3)	3 (8.6)

In contrast to the reasons for disclosure to partners, the most frequent reason given for disclosure to parents (52.5%), other relatives (59.2%) and friends (82.9%) was because they experienced the relationship as supportive and trusting. For example: “I told … when I came back from the clinic because I was so hurt and wanted someone to share the pain with me” (woman about a friend); “There is no other person but my mother I could tell, knowing that she'd help me. She understands. A mother is a mother.” Of those who disclosed to their parents, 20% reported that they had done so because they felt they owed their parents the truth. A few respondents (15%) felt that their parents had to know about their status since it would explain their behavior, illness and death: “I wanted them to know what killed me and ask them to look after my children when I am dead.”

Reasons for non-disclosure

Reasons given for non-disclosure were diverse (Table 2). A large percentage of women indicated that they intend to disclose, but did not feel ready to disclose to their partners (27.8%), parents (21.5%) and other relatives (22.1%). They felt that they first had to deal with the diagnosis emotionally, wait for delivery of the baby, discuss the results in person or wait for their partners to test. Of those who had not disclosed to partners, 31.8% were fearful, specifically of abandonment (7.3%), of being blamed (6.6%), of violence (6%) and emotional abuse (6%). These fears were often based on what their partners had

previously said about HIV, for example: “I do not know how to tell him. He often says he would kill me if I told him that I'm infected because he does not have HIV.”

Table 2. Reasons for not disclosing to members of social network.

Reasons*	Partner (*n*=151) *n* (%)	Parents (*n*=261) *n* (%)	Other relatives (*n*=253) *n* (%)	Friends (*n*=180) *n* (%)	Community members (*n*=240) *n* (%)
Notes: *Total *n* is greater than sample size, as some respondents provided more than one reason for non-disclosure					
Fear	48 (31.8)	42 (16.1)	42 (16.6)	26 (14.4)	48 (20)
Abandonment	11 (7.3)	12 (4.6)	11 (4.3)	15 (8.2)	13 (5.4)
Blame/anger	10 (6.6)	3 (1.1)	2 (0.8)	3 (1.6)	4 (1.7)
Violence	9 (6)	1 (0.4)	2 (0.8)	0	0
Emotional abuse/discrimination	9 (6)	17 (6.5)	21 (8.3)	8 (4.4)	32 (13.3)
General fear	15 (9.9)	17 (6.5)	10 (4.0)	5 (2.7)	6 (2.5)
Not ready/waiting	42 (27.8)	56 (21.5)	56 (22.1)	26 (14.4)	23 (9.6)
Emotionally not ready	24 (15.8)	42 (16.1)	44 (17.4)	21 (11.4)	23 (9.6)
Delivery of baby	5 (3.3)	3 (1.1)	2 (0.8)	0	0
Partner's test results	9 (6)	0	1 (0.4)	0	0
Want to discuss in person	4 (2.6)	11 (4.2)	9 (3.6)	5 (2.7)	0
Lacks regular contact	20 (13.2)	47 (18)	28 (11.1)	10 (5.6)	0
Protect others from results	8 (5.3)	58 (22.2)	22 (8.7)	7 (3.9)	0
Not trusting relationship	6 (4)	33 (12.6)	63 (24.9)	83 (46.1)	93 (38.8)
Person won't understand HIV	6 (4)	8 (3.1)	4 (1.6)	2 (1.1)	7 (2.9)
Does not intend to tell	4 (2.6)	4 (1.5)	22 (8.7)	19 (10.6)	47 (19.6)
Does not know how to tell	2 (1.3)	1 (0.4)	1 (0.4)	0	1 (0.4)
Other reason	15 (9.9)	12 (4.6)	15 (5.9)	7 (3.9)	21 (8.8)

The women tended to be protective of their parents (22.2%). For example: “My mother is sick. She had a stroke. I can't tell her because it will affect her health.” Other reasons for

not disclosing to parents were fear (16.1%) - primarily of emotional abuse and discrimination (6.5%) - not having a trusting relationship with them (12.6%) or not having regular contact (18%).

The most frequent reasons given for not disclosing to other relatives, friends or community members was the lack of trusting relationships and fear of emotional abuse or discrimination and abandonment. For example: “I am not close to them and don't know what they will say behind my back.” A notable percentage did not intend to disclose at all and a few indicated that they did not know how to disclose to others.

Reactions after disclosure

In general the women reported four different types of reactions to their disclosure. Some people expressed denial, disbelief or shock. Others were overtly emotional and expressed being sad, hurt, fearful or angry. The reaction of others was to be supportive. A small proportion of people appeared to have no reaction, were quiet or indifferent (Table 3).

Table 3. Reactions of people to disclosure of HIV status.

Reactions*	**Partner (*n*=151) *n* (%)**	**Parents/caregiver (*n*=49) *n* (%)**	**Other relatives (*n*=58) *n* (%)**	**Friends (*n*=35) *n* (%)**
Notes: *Total *n* is greater than sample size, as some respondents provided more than one reaction to disclosure, and disclosed to multiple individuals.				
Denial/disbelief				
Denial/disbelief	46 (30.5)	3 (6.1)	7 (12.1)	1 (2.9)
Shock	22 (14.6)	5 (10.2)	9 (15.5)	4 (11.4)
Overt expression of emotion				
Sadness/hurt/fear	23 (15.2)	18 (36.7)	11 (19)	5 (14.3)
Anger	7 (4.6)	1 (2)	0	0
Other negative emotion	9 (6)	0	1 (1.7)	3 (8.6)
Supportive				
Supportive/accepting	18 (11.9)	18 (36.7)	28 (48.3)	20 (57.1)
Indifference				
No reaction/quiet/indifferent	18 (11.9)	2 (4.1)	2 (3.4)	1 (2.9)
Other response	8 (5.3)	2 (4.1)	0	1 (2.9)

For partners, the most frequent reaction was one of denial/disbelief (30.5%), shock (14.6%) or an overtly emotional reaction (25.8%), while only 11.9% reacted with support and acceptance. In contrast, parents (36.7%), relatives (48.3%) and friends (57.1%) tended to have more supportive and accepting reactions. Parents in particular, also tended to react with sadness, hurt or fear (36.7%). For example: “She was very hurt, she cried but she accepted and was supportive. I felt better after telling her.”

Anger and other negative reactions were infrequent, occurring overall in only 7.1% of the people women disclosed to. Partners' lack of reaction and indifference was mentioned by 11.9% of the women. For example: “He just looked at me and turned the other way without saying a word. He acts as if I did not tell him a serious thing.”

Adverse consequences following disclosure

The women's reports of adverse consequences after having disclosed their HIV-status are given in Table 4.

Table 4. Adverse consequences following disclosure of HIV status.

Adverse consequence	**Number experiencing consequence (*n*=173) *n* (%)**
I have felt hurt by how people have reacted to learning about my HIV	29 (16.8)
People act as though it is my fault I am HIV-positive	9 (5.2)
I have been called bad names because I am HIV-positive (verbal abuse)	4 (2.3)
I have been shouted at because I am HIV-positive	4 (2.3)
My husband/partner left me because I am HIV-positive	4 (2.3)
People have avoided touching me because of my HIV	3 (1.7)
I have been hit or physically hurt because I am HIV-positive	3 (1.7)
People have threatened to kill me because I am HIV-positive	2 (1.2)
People do not want me around their children because of my HIV	1 (0.6)
I have lost friends because I'm HIV-positive	1 (0.6)
People do not want me to come to their houses because I am HIV-positive	1 (0.6)

Of the 173 women who had disclosed, 35 (20.2%) had experienced some kind of adverse consequences and 13 of these reported experiencing more than one adverse consequence.

The most frequent consequence was feeling hurt by people's reaction to their HIV status (16.8%). A small number of women experienced serious negative consequences, such as being abandoned by their partners (2.3%), physically hurt (1.7%) or threatened with death (1.2%).

Discussion

Our findings show that nearly two-thirds (59%) of pregnant women disclosed their HIV status to at least one person shortly after receiving the diagnosis. Compared to other research performed in South Africa (Kuhn et al., 1999; Sethosa & Peltzer, 2005) this is a relatively high level of disclosure, while it is lower than in other studies (Farquar et al., 2001; Skogmor et al., 2006; Varga et al., 2006). Women disclosed selectively, mostly to only one person, usually a partner or a close family member. The women disclosed to a partner primarily to raise awareness of the risk of HIV and out of a sense of responsibility to their partners, which was also found in research elsewhere (Kumar, Kilaru, Forde, & Kumari, 2007; Medley et al., 2004). In contrast, women mainly disclosed to their parents, other family members and friends to gain support for themselves. This need for support has also been emphasized in research done in the US (Derlega, Winstead, Greene, Serovich, & Elwood, 2004; Kalichman et al., 2003; Simoni et al., 1995).

In contrast to previous South African research on pregnant women, where the primary motivation for disclosure was due to prevention and care for the infant (Varga et al., 2006), it is surprising that only 4.8% of our women stated that they disclosed to elicit support for the protection of their babies. This is likely due to the fact that women in our sample had only recently tested positive and were still dealing with the trauma of infection. This is supported by the high number of women who said they needed more time before they could disclose. Women in our sample were interviewed during pregnancy (mean gestational age of 28 weeks) compared to women in the study by Varga et al. (2006), who were enrolled at 3-months post-delivery and were reflecting on motivations for disclosure during pregnancy. It is possible that their experience in the PMTCT-program colored this retrospection. Women in our sample were motivated to disclose their status mainly to prevent transmission to their partners (31.7%) and to gain support from others, more than to protect their unborn babies. This may indicate a need for more counseling sessions additional to post-test counseling, focusing on choices related to infant feeding when the baby is born.

Four key aspects could be identified as playing a role in the hesitation to disclose. The most prominent and well-documented aspect was related to fear and attempts to protect themselves from other's negative reactions (Maman, Mbwambo, Hogan, Kilonzo, & Sweat, 2001; Medley et al., 2004). Secondly, some women were not ready to disclose their status, mainly because they needed time to come to terms with the diagnosis. As described by Kimberly and Serovich (1996), disclosure is a process in which individuals have first to deal with the diagnosis and then to decide to whom to disclose and how best to do so. Unfortunately, during pregnancy there is little time before childbirth, when decisions about infant feeding are important and may require the understanding and support of others. A third aspect that played a role in disclosure was women's evaluation

of the quality of their relationships. They were more likely to disclose in relationships with family and friends they regarded as trusting and supportive. A reason for non-disclosure was a desire to protect especially parents from the burden of the HIV diagnosis. Protection from the diagnosis has been explained as a means to maintaining support (Brandt, Dawes, & Bray, 2006), but could also be out of concern for the parents' well-being, reflecting the value that women attach to relationships.

The results of this study illustrate the complexity of women's decisions about disclosure. Women not only consider their own needs for support and fear of abandonment and discrimination, but also consider the safety of their partners and the emotional well-being of their parents. This reaction is in line with the accepted gender role of women to attend to relationships and to nurture others (Abdool-Karim, 1998) and reflects on the importance of interconnectedness in a socio-oriented African culture, which emphasizes collective values and communal outcomes (Triandis, 1995).

After disclosing their status women experienced mixed reactions. Partner reactions of disbelief and shock could be explained by the partner's fears of being infected, possibly guilt of having transmitted the infection or other factors relating to mistrust in the relationship. These reactions were reported shortly after disclosure (less than a month for most women) and could obviously change over time. In contrast, despite fear of rejection, almost half of the women who disclosed to family and friends received acceptance and support. However, this was a selective process where women were more likely to disclose to family and friends whom they expected would support them, and only a small minority eventually did disclose. While a few women experienced serious adverse consequences, such as death threats (1.2%) and abandonment by their partners (2.3%), the majority of women (79.8%) experienced no adverse consequences due to disclosure of their status. Women reported much more acceptance and support. These findings confirm results of Medley et al. (2004) and Mokhoka (2000) that women experience fewer adverse reactions after disclosure than anticipated.

Conclusion

This research highlights the complexity of the decisions HIV-positive pregnant women need to make in the short time between diagnosis and the birth of their babies. Many women indicated that they needed more time to come to terms with the diagnosis before being willing to disclose. Yet, during pregnancy there is an urgency for a woman to make choices that may impact on her own health and possible HIV transmission to her partner and baby. Healthcare workers need to recognise the different dynamics involved in disclosure to partners and to family and friends. Disclosure to partners is often complicated by the risk of infection and complexities in intimate relationships. Since women fear adverse consequences more than they are reported, helping individuals to obtain realistic outcome expectations should be integrated into post-test counselling (Doull et al., 2006). Focusing on positive outcomes of disclosure while assessing the risk for negative outcomes should be key in enhancing the effectiveness of post-test counselling and increasing disclosure among HIV-positive women and, thereby, potentially decreasing the risks of HIV transmission to their partners and infants. This

research also highlights the need for the allocation of more effort and resources into counselling and support to assist women in making decisions about disclosure. Pre- and post-test counseling delivered once only, mostly by volunteers (Department of Health, 2000; Solomon et al., 2004), is not sufficient to assist women in dealing with these complexities related to their diagnosis, disclosure and the protection of their partners and their babies. HIV-positive individuals, and pregnant women in particular, need continued counseling and support to help them cope with the many challenges of living with HIV.

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Notes

1. The Serithi project is a longitudinal study in which women diagnosed HIV-positive during pregnancy were enrolled and followed until two years after delivery to examine the role of psychological and nutritional factors on disease progression. Quantitative results of the study are published elsewhere.

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