

HIV SEROSTATUS DISCLOSURE PATTERN AMONG PREGNANT WOMEN IN ENUGU, NIGERIA

H. U. EZEGWUI*, E. E. NWOGU-IKOJO†, J. O. ENWEREJI* AND C. C. DIM*

**Department of Obstetrics and Gynaecology, University of Nigeria Teaching Hospital, Enugu, Nigeria and †Maternity Unit, Annunciation Specialist Hospital, Emene, Enugu, Nigeria*

Summary. This study was carried out in two medical facilities in Enugu, Nigeria, from September to November 2007. An interviewer-administered questionnaire was used to collect data from HIV-positive pregnant women accessing PMTCT (prevention of maternal-to-child transmission) services at the two centres. Ninety-two women were interviewed: 89 (96.7%) had disclosed their status, while 3 (3.3%) had not. Of the 89 women who had disclosed, 84 (94.4%) had disclosed to partners, 82 (92.1%) to husbands, 2 (2.2%) to fiancés, 18 (20.2%) to sisters, 13 (14.6%) to mothers, 10 (11.2%) to brothers, 10 (11.2%) to fathers and 10 (11.2%) to priests. Fifty-two (58.4%) gave emotional support as the reason for disclosure and 46 (51.7%) gave economic and financial support as reasons. Fifty-six (62.9%) reported understanding from partner as a positive outcome and 44 (49.4%) reported financial support. Forty-six (51.7%) reported no negative outcome. Serostatus disclosure rate in this study was high with most women disclosing to their partners.

Introduction

Antenatal HIV counselling and testing (HCT) is one of the strategies to prevent maternal-to-child transmission (PMTCT) of HIV to the newborn child. Routine HCT is offered to pregnant women in Nigeria at major hospitals offering PMTCT services with the option of opting out. Clients receive group pre-test education at the antenatal clinic and are then offered the HIV test. Uptake of routine HIV testing after group education is greater than with voluntary individual pre-test counselling (Creek *et al.*, 2007). Individual post-test counselling is given to all women, during which the test result is disclosed. Women who test positive are usually encouraged to bring their partners for testing.

Women who test positive are encouraged to disclose their status to trusted relatives in order to get the support they need to continue care. Mothers are the primary care-givers for their newborn infants in Nigerian communities. When

possible, the woman's mother or other female relatives may help with care. Men are rarely involved in providing direct care for children, but provide money for expenses involved in providing care. The infant's parents primarily make decisions about infant care. Disclosure is thus important, especially to spouse, to support infant feeding choices made in order to avoid mixed feeding. This is very important for women who choose breast milk substitutes such as infant formula as lack of support from spouse and family to both support her through her decision and provide the funds for buying infant formula may lead to mixed feeding and thus increase risk of transmission of HIV.

Disclosure is associated with risks due to the stigma attached to HIV infection (Koegh *et al.*, 1994). Negative consequences of positive serostatus disclosure include stigmatization, blame, abandonment and even physical violence (Temmerman *et al.*, 1995; Gielen *et al.*, 1997; Koenig *et al.*, 2002; Medley *et al.*, 2004; Varga *et al.*, 2005). The fear of these negative consequences can itself be a reason for non-disclosure (Heyward *et al.*, 1993; Koegh *et al.*, 1994; Antelman *et al.*, 2001; Maman *et al.*, 2001; Medley *et al.*, 2004). A previous study on domestic violence against pregnant Nigerian women in Enugu, Nigeria, found that 37.2% had a previous history of abuse, with 13% having been abused in the preceding 12 months and 11.0% within the index pregnancy (Ezegwui *et al.*, 2003).

Testing and disclosure is usually a planned event (Varga *et al.*, 2005). Pregnancy, however, presents a unique difficulty for the woman, in that the decision to take the test may not have been discussed with her partner. Routine HCT, also, places the burden of facing up to potential infection, and subsequent decisions on how to deal with this knowledge (including all the moral pressure that comes with it) entirely on the shoulders of the woman. This makes disclosure more difficult (Varga *et al.*, 2005). The risk of possible partner discordance after the tests further makes disclosure difficult due to fear of breakdown of relationships and withdrawal of support from partner (Ateka, 2006). Thus, prior discussion with her partner before testing makes disclosure of serostatus results more likely (Maman *et al.*, 2003). Antenatal HCT is routinely offered at most antenatal clinics at public General and Teaching Hospitals, and in some faith-based hospitals in Nigeria. It is not certain how widespread this information may be available to the public as most of these services are about one to two years old. For women who disclose, the need to ensure the well-being of the infant is a strong motivating factor (Varga *et al.*, 2005).

There are positive aspects of disclosure, such as social and financial support from partner and families, improved psychological and physical well-being, access to appropriate care facilitated by the family, support for infant feeding options (especially breast milk substitute) and support to continue with care (Koegh *et al.*, 1994; Antelman *et al.*, 2001; Varga *et al.*, 2005).

The study seeks to determine the HIV serostatus disclosure pattern amongst women accessing PMTCT services at two centres in Enugu, south-eastern Nigeria.

Methods

The study was carried out at the University of Nigeria Teaching Hospital (UNTH), Enugu, Nigeria, and the Annunciation Specialist Hospital (ASHE), a Roman Catholic

mission hospital in Emene, Enugu, Nigeria. Enugu is located in the south-east Nigeria geopolitical zone, mostly populated by the Ibo ethnic group. The Ibos over the years have become westernized, most marriages are monogamous, and polygamy is declining. Enugu is the capital of Enugu State. The study population consists of women accessing PMTCT services at both centres between 1st September and 30th November 2007. Services offered by these centres include antenatal HIV testing and counselling, provision of antiretroviral (ARV) drugs, treatment of opportunistic infections and infant feeding option counselling, and both have strong linkages with adult and paediatric antiretroviral therapy (ART) services within their facilities. The UNTH commenced PMTCT services in July 2002, while ASHE commenced PMTCT services in January 2007. These services and all antiretroviral drugs (including treatment for opportunistic infections) are free. Clients still have to pay for other ancillary services such as delivery, evacuation of retained products of conception and inpatient care for PMTCT clients.

The aim of the research was explained to patients, and verbal consent obtained. Patients were reassured that all information given was confidential and that there was nothing in the questionnaire to identify them individually.

An interviewer-administered questionnaire was used by the authors to collect relevant data. The questionnaire was administered on consenting consecutive women seen at the clinic in both facilities. The data were analysed using the Epi Info 2002 statistical package.

Results

Ninety-two women were interviewed during the study period. Eighty-nine women (96.7%) had disclosed their status, while three (3.3%) had not. Of the 92 respondents, 80 were from the UNTH and twelve from ASHE. All the three clients who had not disclosed their status were from the UNTH ($p=0.4952$). Table 1 shows the participants' sociodemographic characteristics. Most of them were married. Of the 89 women who had disclosed their status, 84 women (94.4%) had disclosed to their partners.

Table 2 shows the serostatus disclosure pattern amongst the respondents and Table 3 the reasons for disclosure. Reasons given by those grouped as 'others' include husband was positive in two (2.2%), baby tested positive during illness in one (1.1%), because of love for spouse in one (1.1%), both tested together in one (1.1%), husband was positive and made her test in one (1.1%), loss of her baby in one (1.1%), forced to disclose by her husband in one (1.1%), had a major illness in one (1.1%) and to find out source of infection in one (1.1%).

Tables 4 and 5 show the positive outcomes and negative effects after disclosure, respectively.

Discussion

The 96.7% disclosure rate in this study is quite high, similar to another study amongst HIV-positive mothers in Johannesburg, South Africa, made up mostly of unemployed women and unskilled workers with the need to ensure well-being of their child a

Table 1. Sociodemographic characteristics of respondents

Characteristic	Disclosed				Total	%
	Yes	%	No	%		
Age group (years)						
15–19	2	2.2	0	0.0	2	2.2
20–34	83	93.3	1	33.3	84	91.3
≥ 35	4	4.5	2	66.7	6	6.5
Total	89	100.0	3	100.0	92	100.0
Marital status						
Married	84	94.4	3	100.0	87	94.6
Single	5	5.6	0	0.0	5	5.4
Total	89	100.0	3	100.0	92	100.0
Education						
Primary	10	11.2	1	33.3	11	12.0
Secondary	51	57.3	1	33.3	52	56.5
Higher	28	31.5	1	33.3	29	31.5
Total	89	100.0	3	100.0	92	100.0
Employment status						
Unemployed	37	41.6	1	33.3	38	41.3
Unskilled	10	11.2	1	33.3	11	12.0
Semi-skilled	32	36.0	1	33.3	33	35.9
Skilled	10	11.2	0	0.0	10	10.9
Total	89	100.0	3	100.0	92	100.0
Time since diagnosis						
<6 months	20	22.5	0	0.0	20	21.7
6–12 months	19	21.3	1	33.3	20	21.7
1–2 years	27	30.3	1	33.3	28	30.4
≥ 3 years	23	25.8	1	33.3	24	26.1
Total	89	100.0	3	100.0	92	100.0
Disclosed to partner						
Yes	84	94.4	0	0.0	84	91.3
No	5	5.6	3	100.0	8	8.7
Total	89	100.0	3	100.0	92	100.0
Partner tested for HIV						
Yes	77	86.5	0	0.0	77	83.7
No	6	6.7	2	66.7	8	8.7
I don't know	6	6.7	1	33.3	7	7.6
Total	89	100.0	3	100.0	92	100.0
Partner's HIV status						
Positive	36	40.4	0	0.0	36	39.1
Negative	39	43.8	0	0.0	39	42.4
I don't know	14	15.7	3	0.0	17	18.5
Total	89	100.0	3	100.0	92	100.0

Table 2. Disclosure pattern amongst women

To whom disclosed ^a	<i>N</i>	% ^b
Brother	10	11.2
Father	10	11.2
Fiancé	2	2.2
Friend	3	3.4
Husband	82	92.1
Mother	13	14.6
Mother-in-law	2	2.2
Priest	10	11.2
Sister	18	20.2
Sister-in-law	3	3.4

^aDisclosures to more than one person in some instances.

^bPercentage of 89 women who had disclosed.

Table 3. Reasons for disclosure

Reason ^a	<i>N</i>	% ^b
Economic & financial support	46	51.7
Emotional support	52	58.4
Social support	21	23.6
Prayers/spiritual support	14	15.7
None given	17	19.1
Others	10	11.2

^aMore than one reason given by respondents.

^bPercentage of 89 women who had disclosed.

major motivating factor (Varga *et al.*, 2005). Emotional (58.4%) and economic support (51.7%) are the main reasons for disclosure in this study, and this shows that the respondents understand the importance of disclosure to trusted people who could provide the needed support for them to continue care and support their babies. However, Medley *et al.* (2004) in a review of seventeen studies (fifteen from sub-Saharan Africa) on rates, barriers and outcomes of serostatus disclosure and its implications for PMTCT programmes from developing countries found that several studies report low serostatus disclosure rates with fear of accusations of infidelity, abandonment, discrimination and violence being the main barriers to disclosure. The majority of the women who had disclosed were married. This indicates the greater likelihood of people in more stable relationships to disclose their status. A prospective study among HIV-infected, post-parturient women in Barbados showed amongst others that married women were more likely to disclose their status (Kumar *et al.*, 2006); also, Antelman *et al.* (2001) in a study in Dar es Salaam, Tanzania, showed that people who were in longer lasting relationships (>2 years) were more likely to

Table 4. Positive outcomes after disclosure

Outcomes ^a	<i>N</i>	% ^b
Acceptance/understanding from family	18	20.2
Financial support	44	49.4
Receiving kindness	28	31.5
Receiving prayers	14	15.7
Understanding from partner	56	62.9
None	24	27.0

^aMultiple outcomes reported by respondents.

^bPercentage of 89 women who had disclosed.

Table 5. Negative outcome after disclosure

Reason ^a	<i>N</i>	% ^b
Abandonment	13	14.6
Blame	21	23.6
Divorce	1	1.1
Ill-treatment from partner	6	6.7
Rejection by family	16	18.0
Stigmatization	33	37.1
Violence/assault	7	7.9
None	46	51.7

^aSome women reported more than one negative outcome.

^bPercentage of 89 women who had disclosed.

disclose to their partners. Those who are in more stable relationships may be more likely to have a better understanding of themselves and trust for one another. However, two (66.7%) of the three women who had not disclosed were also married, showing that fears about negative outcomes still hinder some women from disclosing their HIV status to their spouses. Of the overall study population, 8.7% had still not disclosed to their partners, highlighting that there is still the fear of possible negative outcomes of disclosure. Couple counselling could be a means of easing disclosure amongst partners, as shown in a study in Lusaka, Zambia (Semrau *et al.*, 2005).

Amongst the 89 women that had disclosed their status, 94.4% had disclosed their status to their partners, and 86.5% of their partners had been tested for HIV. Thus disclosure, especially to partners, may encourage them to go for tests and enable them to adopt health behaviour that reduces risk of transmitting the virus and re-infection with new strains. This is important during pregnancy to avoid re-infection of these women with new strains of the virus, and thus increase risk of drug resistance and vertical transmission. A study in Barbados among post-parturient women showed that partners of women who had disclosed their status were more likely to test for HIV

(Kumar *et al.*, 2006). There is a partner HIV discordance rate of 42.4 % in this study, similar to findings (40%) at three prenatal sites in Texas, USA, in a mostly black (67.5%) study population (Ateka, 2006). While Highly Active Antiretroviral Therapy (HAART) is universally accessible in Texas, USA, and may account for lower rate of transmission to partners, access to ARVs is still limited in the Nigerian practice environment. Thus, the reason for this high discordance rate is not immediately clear and will need further study to elucidate.

The women disclosed mostly to their husbands and partners, similar to other studies in Dar es Salaam, Tanzania (Antelman *et al.*, 2001), Johannesburg, South Africa (Varga *et al.*, 2005), and Texas, USA (Ateka, 2006). This is important in initiating safer sex practices among couples and encourages support from partners for infant feeding choices made by the mothers, including the provision of money for the purchase of infant milk formula. Sexual partners, also, do meet a specific need for which they may not be easily substituted (Ateka, 2006). Immediate female relatives (sisters, 20.2%, and mothers, 14.6%) were the next most important group, similar to other studies among pregnant women in Tanzania (Antelman *et al.*, 2001) and South Africa (Varga *et al.*, 2005). These are usually strong sources of social support in Nigerian communities, and in some situations may actually provide the needed financial support to continue care. Disclosure to immediate male relatives (fathers, 11.2%, and brothers, 11.2%) was next in importance. Immediate male relatives are important in the Ibo social context. They provide a form of security to married sisters as they sometimes intervene to stop or prevent abuse of their female relatives by their partners, help provide economic support (especially for issues related to medical care), and are usually the providers of accommodation and financial support to their immediate female relatives when marriages break down in Ibo communities. Mothers-in-law, sisters-in-law and friends were not popular groups for the women to disclose their serostatus to. These groups may not be very effective sources of support and may rather be sources of conflict. In the Ibo social context, marriages are deemed to have been contracted between families, and thus each family acts to ensure the perceived best interest of its own member. Thus, the fear of being accused of being the source of the infection may discourage women from disclosing to in-laws. When a relative accompanies women to antenatal clinic in Nigerian communities, it is usually their mothers or sisters. Thus, they are a readily available source of support. Disclosure of HIV status to friends was not common in a study among tuberculosis patients in South Africa (Daftary *et al.*, 2007). Disclosure to friends may not be seen as necessary, with the fear that the information could be spread to the immediate community. Of the women that disclosed their status, 11.2% disclosed to their priests, the same proportion that disclosed to fathers and brothers respectively, showing they could be an important support group in the fight against HIV. Thus, education of the clergy on modes of transmission, prevention of HIV, on counselling skills and on ways of providing social support will equip them to play this role effectively as the need arises.

Emotional support was the main reason for disclosure (58.4%) among the women who disclosed their status. It is thus important for these women that their confidants and loved ones continue support after disclosure. A study among drug users in Indonesia showed that those who tested positive expected increased emotional

support from care-givers (health professionals), family/relatives, employers and peers (Ford *et al.*, 2004). Thus, support, encouragement and the reassurance that someone cares motivates those who test positive to continue care. Economic and financial support was the next most important reason for disclosure (51.7%). These women need money for transportation costs to health facilities and for good quality food to stay healthy amongst other needs. These are important to ensure the women continue to attend their clinics, receive PMTCT services and are able to implement the infant feeding choices they make, as the need to have a healthy baby is an underlying motivation for disclosure (Varga *et al.*, 2005). Social support was given as the reason for disclosure by 23.6%. The gap between the desire for emotional support and social support may be that support from family and relatives is more important to women than support from the immediate community. Prayers and spiritual support were given as reasons for disclosure by 5.7%. Religious groups can be trained to provide additional social support for these women, and even serve as the main source of support where this is not forthcoming from families and relatives. They can also be used to pass clear and effective health-related information about HIV to members.

Of the women who had disclosed their serostatus, 62.9% reported understanding from their partner as a positive outcome after disclosure. Partners who show understanding may be more willing to support these women, even after disclosure of their positive serostatus as in studies in Tanzania (Maman *et al.*, 2003; Varga *et al.*, 2005). Financial support was the next most reported positive outcome, which is very important for women to continue to access care and provide infant milk formula for their babies for those who choose that option. Almost a third of respondents reported receiving kindness. However, Varga *et al.* (2005) in a study in South Africa showed that showing too much concern or 'over-care' can make HIV-positive mothers feel guilty, trapped and isolated. Only 20.2% of women who had disclosed met acceptance from family. This can discourage disclosure, if women fear that their families will not accept them and show support. Of the women who disclosed, 15.7% reported receiving prayers. Praying with people is a way of showing support and encouragement among Nigerians, especially among family members. Disclosure will not always lead to positive outcomes: 27% reported no positive outcome after disclosure. It will be important to provide intervention programmes to both provide social support and possibly financial assistance where necessary to enable such women to continue caring for themselves and their babies.

Of the women who had disclosed their positive status, 51.7% reported no negative outcome after disclosure. This should encourage women to disclose their status if they know that they are not likely to suffer any negative outcome. While almost half the women experienced negative outcomes, increased public health education and information about HIV/AIDS, especially to men, will help reduce the negative consequences of disclosure. Other women reported various negative outcomes such as stigmatization (37.1%), blame (23.6%), rejection by family (18.0%), abandonment (14.6%), violence/assault (7.9%) and ill-treatment from partner (6.7%). Only one woman (1.1%) reported divorce as a negative outcome. Fear of partner's reaction has been identified as a barrier to serostatus disclosure (Maman *et al.*, 2001, 2003; Antelman *et al.*, 2001; Varga *et al.*, 2005; Kumar *et al.*, 2006).

The serostatus disclosure rate in this study is high, with a large proportion disclosing to their partners. The negative outcomes after disclosure by some women may continue to pose a barrier to disclosure by other women. Continued public health education should highlight the dangers of these negative outcomes in preventing the spread of HIV and reduction in maternal-to-child transmission of HIV/AIDS. Deliberate effort should be made to target men to enable them to have the information they need to make positive choices when their partners do disclose their positive status to them. Intervention programmes to provide social and economic support for those who experience negative outcomes after disclosure should be put in place.

References

- Antelman, G., Smith Fawzi, M. C., Kaaya, S., Mbwambo, J., Msamanga, G. I., Hunter, D. J. *et al.* (2001) Predictors of HIV-1 serostatus disclosure: a prospective study among HIV-infected pregnant women in Dar es Salaam, Tanzania. *AIDS* **15**, 1865–1874.
- Ateka, G. K. (2006) HIV status disclosure and partner discordance: a public health dilemma. *Public Health* **120**, 493–496.
- Creek, T. L., Ntunmy, R., Seipone, K., Smith, M., Mogodi, M., Smit, M. *et al.* (2007) Successful introduction of routine opt-out HIV testing in antenatal care in Botswana. *Journal of Acquired Immune Deficiency Syndrome* **45**, 102–107.
- Daftary, A., Padayatchi, N. & Padilla, M. (2007) HIV testing and disclosure: a qualitative analysis of TB patients in South Africa. *AIDS Care* **19**, 572–577.
- Ezegwui, H. U., Ikeme, A. C. & Onwasigwe, C. N. (2003) Domestic violence against pregnant Nigerian women. *Tropical Journal of Obstetrics and Gynaecology* **20**, 118–118.
- Ford, K., Wirawan, D. N., Sumantera, G. M., Sawitri, A. A. S. & Stahre, M. (2004) Voluntary HIV testing, disclosure, and stigma among injection drug users in Bali, Indonesia. *AIDS Education and Prevention* **16**, 487–498.
- Gielen, A. C., O'Campo, P., Faden, R. & Eke, A. (1997) Women's disclosure of HIV status: experience of mistreatment and violence in an urban setting. *Women's Health* **25**, 19–31.
- Heyward, W. L., Batter, V. L., Mbuyi, M. N., Mbu, L., St Louis, M. E. & Munkolenkole, K. *et al.* (1993) Impact of HIV counselling and testing among child-bearing women in Kinshasa, Zaire. *AIDS* **7**, 1633–1637.
- Koegh, P., Allen, S., Almedal, C. & Temahagali, B. (1994) The social impact of HIV infection on women in Kigali, Rwanda: a prospective study. *Social Science and Medicine* **38**, 1047–1053.
- Koenig, L. J., Whitaker, D. J., Royce, R. A., Wilson, T. E., Callahan, M. R. & Fernandez, M. I. (2002) Violence during pregnancy among women with or at risk for HIV infection. *American Journal of Public Health* **92**, 367–370.
- Kumar, A., Waterman, I., Kumari, G. & Carter, A. O. (2006) Prevalence and correlates of HIV serostatus disclosure: A prospective study among HIV-infected postparturient women in Barbados. *AIDS Patient Care and STDs* **20**, 724–730.
- Maman, S., Mbwambo, J., Hogan, N. M., Kilonzo, G. P. & Sweat, M. (2001) Women's barrier to HIV-1 testing and disclosure: challenges for HIV-1 voluntary counseling and testing. *AIDS Care* **13**, 595–603.
- Maman, S., Mbwambo, J. K., Hogan, N. M., Weiss, E., Kilonzo, G. P. & Sweat, M. D. (2003) High rates and positive outcomes of HIV-serostatus disclosure to sexual partners: reason for cautious optimism from voluntary counselling and testing clinics in Dar es Salaam, Tanzania. *AIDS and Behaviour* **7**, 373–381.

- Medley, A., Garcia-Moreno, C., McGill, S. & Maman, S.** (2004) Rates, barriers, and outcomes of HIV serostatus disclosure among women in developing countries: implications for prevention of mother-to-child transmission programmes. *Bulletin of the World Health Organization* **82**, 299–307.
- Semrau, K., Kuhn, L., Vwalika, C., Kasonde, P., Sinkala, M., Kankasa, C. et al.** (2005) Women in couple antenatal HIV counselling testing are not more likely to report adverse social events. *AIDS* **19**, 603–609.
- Temmerman, M., Ndinya-Achola, J., Ambani, J. & Piot, P.** (1995) The right not to know HIV test results. *Lancet* **345**, 969–970.
- Varga, C. A., Sherman, G. G. & Jones, S. A.** (2005) HIV transmission in the context of vertical transmission: HIV-positive mothers in Johannesburg, South Africa. *AIDS Care* **18**, 952–960.