

## Issues Surrounding HIV Status Disclosure: Experiences of Seropositive Women in Lagos, Nigeria

### Abstract

**Background:** Disclosure of human immunodeficiency virus (HIV) seropositivity by infected women is crucial in HIV control. To determine the rates, patterns, effects, and determinants of disclosure of status among HIV-positive women in Lagos, Nigeria. **Methods:** This was a descriptive cross-sectional study. Simple random sampling method was used to select 364 HIV-positive women accessing care in HIV treatment centers in Lagos Island. Data were collected using interviewer-administered questionnaires and analyzed with Epi Info (version 3.5.3). Inferential statistics done was Chi-square test and level of statistical significance was set at <5%. **Results:** Mean age of respondents was  $37.3 \pm 3$  years, and most were married or cohabiting in monogamous families. The disclosure rates were 81.9% to anyone (excluding a health care professional); 60.4% to spouse/sexual partners; and 67.7% disclosed on the same day of diagnosis. Main reasons for disclosure were failing health (49.3%) and a sense of responsibility to the spouse/sexual partner (33.6%). Major reasons for nondisclosure were negative public opinion (84.8%) and fear of losing relationships (40.3%). Positive reactions following disclosure were mostly acceptance: 75.2% (family member) and 72.3% (spouse/sexual partner) while blame was the main negative outcome. Longer duration of diagnosis significantly improved disclosure to anyone ( $P < 0.001$ ). Older age ( $P < 0.001$ ) and awareness of spouse/sexual partner's HIV status ( $P < 0.001$ ) significantly improved disclosure to spouse/sexual partner. **Conclusions:** Many respondents had not disclosed their status and require support and counseling to do so. Community education regarding stigmatization should be intensified.

**Keywords:** Human immunodeficiency virus disclosure, human immunodeficiency virus stigmatization, infectious disease control, Nigeria

### Introduction

According to the WHO Global Health Observatory, almost 70 million people have been infected since the onset of the human immunodeficiency virus (HIV) pandemic and about 35 million deaths due to AIDS have been recorded.<sup>[1]</sup> More than three-fifths of the global HIV infection occur in the African region with Sub-Saharan Africa (SSA) being the most severely affected subregion accounting for 71% of people living with HIV worldwide.<sup>[1]</sup> Nigeria, the most populous nation in Africa, had a prevalence rate of 4.1% in 2012;<sup>[2]</sup> Lagos State recorded 5.1%<sup>[3]</sup> while Lagos Island was 9%.<sup>[4]</sup>

In Africa, women in the reproductive age group (15–49 years) have about two times higher risk of infection than males the same age group, and it is even worse (3.4 times) for the younger females aged 15–24 years.<sup>[1]</sup> In this region, more than half of the countries have an HIV prevalence

of about 4% among pregnant women attending antenatal clinic (ANC).<sup>[1]</sup> In SSA, women alone represent 58% of people living with HIV.<sup>[5]</sup> The highest prevalence rates of HIV recorded among young women (15–24 years) attending ANC are found in Southern African countries (17.4%–39.4%)<sup>[6]</sup> while Nigeria reported a prevalence of 4.1% among ANC attendees in the 2010 National HIV Sentinel Seroprevalence Survey.<sup>[7]</sup>

The most common routes identified in the developing world are through heterosexual intercourse<sup>[8]</sup> as well as mother-to-child transmission. Without any prevention measures, the risk of a baby being infected with HIV from the mother in developing countries is 25%–45%.<sup>[9]</sup> Thus, the impact of sexual behaviors and disclosure of status among seropositive women on the transmission and prevention of HIV is of great importance.

Consistent condom use as well as a once-daily use of antiretroviral tablet

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have been found to significantly reduce the risk of HIV transmission among serodiscordant couples.<sup>[10,11]</sup> However, these preventive options can only be effective if the status of the seropositive partner is known to the seronegative partner, hence the need for disclosure. The disclosure of HIV-positive status could be a complex or difficult issue that involves calculated communication of a highly stigmatized, infectious, and life-threatening illness to another person.<sup>[12]</sup> Some people have held back disclosure of their status because they do not know how people will react to the information. However, some women have been able to disclose to husbands, sexual partners, friends, or family members with varying reactions.

From a public health perspective, HIV disclosure has contributed extensively to HIV transmission reduction primarily through condom use and motivation of sexual partners for HIV counseling and testing (HCT)<sup>[13]</sup> as well as overall support from the individual's spouse/sexual partner. Recent HIV prevention initiatives and guidelines are placing greater emphasis on HIV prevention among people already confirmed to be infected. These initiatives are advocating for public health programs and effective counseling and testing procedures that will encourage people to disclose to their sexual partners.<sup>[12]</sup> Disclosure of positive serostatus is critical to encourage access to HIV preventive measures and treatment programs available and thus, an important public health goal in the reduction of the spread of HIV.

Disclosing HIV-positive status to a sexual partner creates room for the couple to make informed choices about their sexual behavior by allowing them to engage in preventive and risk reduction behaviors such as condom use.<sup>[14]</sup> The information helps the individual's family and friends take proper precautions to prevent transmission during their daily interactions with them, increases opportunities of obtaining social support as well as easy access to necessary support and treatment for coping with the illness from relatives and friends. It also encourages motivation for sexual partners to go for HCT. Inclusion of disclosure to sexual partners in the process of HCT can enable other people who are unaware of their status to know on time and so seek appropriate care and treatment.<sup>[12]</sup>

Women who have disclosed their status to partners are presumably more likely to take part in the prevention of mother-to-child transmission (PMTCT) programmes. It becomes easier for an HIV-positive woman who has disclosed her seropositive status to accept and maintain safe, healthy behaviors such as adherence to medications, especially the daily dosages of highly active retroviral therapy, administration of preventive daily nevirapine to the infant, use of breast milk substitute rather than breastfeeding, and other interventions for PMTCT.<sup>[15]</sup> HIV-positive women who for fear of stigmatization or negative reactions from their sexual partners fail to

disclose their seropositive status are more likely to attempt natural conception, and so at risk of both horizontal and vertical HIV transmission.<sup>[16]</sup>

High disclosure rates have been reported in Southern Ethiopia (85.7%)<sup>[15]</sup> and Southeast Nigeria (94.6%),<sup>[17]</sup> whereas lower rates were reported in Zimbabwe (28.6%)<sup>[18]</sup> and Southwestern region of Nigeria (50.9%).<sup>[8]</sup> Some of the deterrents to disclosure of HIV status, especially among African women include fear of violence, abandonment, discrimination, or charges of infidelity. However, many women who were afraid to disclose their HIV status have found that they got a lot of support when they eventually did so. Against this background, the objectives of this study were to determine the disclosure rates, patterns, effects, and determinants of disclosure of HIV status among HIV-positive women in Lagos Island, Lagos, Nigeria.

## Methods

### Study design and participants

This descriptive cross-sectional study was conducted in Lagos Island local government area (LGA). Many slave trade returnees who came back from Brazil settled in Brazilian quarters which is located in Lagos Island. Lagos Island served as the state and federal capital when Lagos state took off as an administrative state in 1968, but when the Federal Capital Territory was created in 1976, Ikeja later became the capital of Lagos state. The poorer eastern side of the island is home to the main wholesale market places and poorer housings in the island.

The island is very congested with a high population density.<sup>[19]</sup> There are four state government-owned hospitals and also various health centers, health posts, and private hospitals within the LGA. These hospitals have been designed to cater for the differing specialties to provide adequate access to medical care for the increasing population.

There are two adult HCT centers within the LGA. These are the General Hospital Odan and Onikan Comprehensive Health Centre and Maternity annex. As at the time of the study, there were 6503 female patients registered in the ART program at the General Hospital Odan and 452 female patients registered at Onikan Comprehensive Health Centre. A minimum sample size was calculated using the formula for descriptive studies,  $n = z^2pq/d^2$ : where  $n$  = the desired sample size (when study population is >10,000);  $z$  = the standard normal deviate, usually set at 1.96 which corresponds to 95% confidence interval;  $P$  = prevalence from previous studies (50.9% - the proportion of women who had disclosed their HIV status in a previous study);<sup>[8]</sup>  $q = 1 - p$ ;  $d$  = degree of accuracy desired, 5% (0.05). Since the study population is <10,000, the actual sample size was then calculated using the second formula:  $nf = n/1 + (n/N)$ : where  $nf$  = the minimum required sample size in population less than 10,000;  $n$  = the desired

sample size when the population is >10,000 (384);  $N$  = the actual population size (6955). This then gave a minimum sample size of 364.

Simple random sampling method was used to select the participants for the study. The total sample size was divided between the two centers using the ratio 1:14 (452:6503). A total of 373 respondents were selected from the General Hospital Odan and 27 respondents from Onikan Comprehensive Health Centre. Eventually, 364 interviews were analyzed.

Both centers operated 3 clinic days/week. At the General Hospital Odan, an average of 250 patients were scheduled for each clinic day which held on Mondays, Wednesdays, and Fridays by the medical records' department, whereas at Onikan Comprehensive Health Centre, an average of 30 patients were scheduled for each clinic day which held on Tuesdays, Wednesdays, and Thursdays. Data were collected over a period of 2 weeks (6 clinic days), 62 respondents from General Hospital Odan and 9 respondents from Onikan Comprehensive Health were interviewed on each of these clinic days.

The list of patients (numbered) scheduled for clinic visit in each facility was obtained, and the required number of patients was selected using table of random numbers. The case notes of those selected were subsequently retrieved, and if the patient did not meet the inclusion criteria, another patient was selected by simple random sampling to replace them until sample size was achieved.

### Data collection

Data were collected between September and October 2013 using pretested, interviewer-administered Questionnaire 1 adapted from a previous study on factors influencing HIV status disclosure,<sup>[20]</sup> and other studies encountered during the literature review in English language. Six interviewers were trained for the data collection: two doctors, two counselors, and two other assistants who were Higher National Diploma Certificate holders. Each Questionnaire took about 10 minutes to be completed. The Questionnaire elicited information on sociodemography, patterns, determinants as well as effects of disclosure.

Ethical approval for the study was obtained from the Health Research and Ethics Committee of Lagos University Teaching Hospital, LUTHHREC No ADM/DCST/HREC/1350. Permission was obtained from the Lagos State Health Service Commission and the Medical Directors of each of the facilities. Written consent was obtained from each respondent before interview, and confidentiality was ensured.

### Data analysis

Data were analyzed electronically using Centre for Disease Control's Statistical Software for Epidemiology, Epi Info (version 3.5.3, CDC Atlanta Georgia, USA) and IBM

Statistical Package for the Social Sciences (version 20, IBM SPSS, Amonk New York, USA). Mean was calculated for continuous variables and proportions for categorical variables. Statistical associations were determined using Chi-square test and the level of significance was set at <5% ( $P < 0.05$ ).

### Results

A total of 364 women were interviewed, about half (46.7%) of the participants were between 31 and 40 years, with a mean age of  $37.3 \pm 3$  years. Majority of the participants were Nigerians (97.8%). Almost two-thirds of the respondents had a secondary education (48.9%) and were unskilled workers (62.7%). Almost half of the respondents had 1 or 2 children (42.1%) and almost all were on ARVs (96.2%) [Table 1].

Of the 364 participants, 51 (14.0%) women had never been married, 75 (20.6%) were divorced, separated, or widowed while 238 (65.4%) were either married or cohabiting. Among the respondents who were married or cohabiting, 182 (76.5%) of them were in monogamous relationships, whereas 56 (23.5%) were in polygamous families. Two hundred and twenty-three (61.3%) were living with their spouses/sexual partners and a total of 201 (55.2%) respondents were aware of their sexual partners' HIV status [Table 1].

A total of 298 (81.9%) participants had disclosed to someone else excluding a health-care professional, of which 190 (63.7%) disclosed to a family member first. Over half (60.4%) of the respondents had disclosed to their spouses/sexual partners. Disclosure was made as early as the same day of diagnosis by more than half (67.8%) of the respondents [Table 2].

The major reason for disclosure among those respondents who had disclosed to other persons apart from a health-care professional was their failing health (49.3%), whereas those who had disclosed to their spouses/sexual partners felt a sense of responsibility to do so (33.6%). Majority of the respondents who had not disclosed to other persons apart from a health-care professional attributed their nondisclosure to a negative public opinion (84.8%), whereas those who had not disclosed to their spouses had not disclosed due to the fear of losing their relationships (40.3%) [Table 3].

There were more positive reactions, majorly acceptance; 75.2% (from anyone else apart from a health-care professional) and 72.3% (from spouse/sexual partner) than negative reactions, majorly blame (3.0% and 6.8%, respectively) following disclosure [Table 4].

More of the respondents who had been diagnosed for 5 years or more had disclosed to someone excluding a health-care professional ( $P < 0.001$ ). Disclosure to spouse/sexual partner was highest among the respondents within

**Table 1: Sociodemographic and family characteristics of respondents (n=364)**

| Variable                                    | Frequency (%) |
|---|---------------|
| Age (years)                                 |               |
| 21-30                                       | 91 (25.0)     |
| 31-40                                       | 170 (46.7)    |
| 41-50                                       | 71 (19.5)     |
| >50   | 32 (8.8)      |
| Mean age                                    | 37.3±3        |
| Nationality                                 |               |
| Nigerian                                    | 356 (97.8)    |
| Non-Nigerian                                | 8 (2.2)       |
| Level of education                          |               |
| No formal education                         | 46 (12.6)     |
| Primary                                     | 75 (20.6)     |
| Secondary                                   | 178 (48.9)    |
| Postsecondary                               | 65 (17.9)     |
| Occupation                                  |               |
| Professional                                | 27 (7.4)      |
| Skilled                                     | 55 (15.1)     |
| Unskilled                                   | 228 (62.7)    |
| Unemployed                                  | 54 (14.8)     |
| Parity                                      |               |
| None  | 66 (18.1)     |
| 1-2   | 153 (42.1)    |
| 3-4   | 106 (29.1)    |
| ≥5  | 39 (10.7)     |
| On ARV                                      |               |
| Yes   | 350 (96.2)    |
| No  | 14 (3.8)      |
| Relationship status                         |               |
| Never married                               | 51 (14.0)     |
| Married/cohabiting                          | 238 (65.4)    |
| Divorced/separated/widowed                  | 75 (20.6)     |
| Family type (n=238)                         |               |
| Polygamous                                  | 56 (23.5)     |
| Monogamous                                  | 182 (76.5)    |
| Living with spouse/sexual partner           |               |
| Yes   | 223 (61.3)    |
| No  | 141 (38.7)    |
| Aware of spouse/sexual partner's HIV status |               |
| Yes   | 201 (55.2)    |
| No  | 163 (44.8)    |

HIV=Human immunodeficiency virus, ARV=Antiretroviral

the 31–40-year age group ( $P < 0.001$ ) as well as among respondents who were aware of their spouse/sexual partner's HIV status ( $P < 0.001$ ). No statistically significant associations were observed between respondent's religion, level of education, and disclosure to spouse/sexual partner [Table 5].

## Discussion

There was a high rate of disclosure to anyone else apart from a health-care professional, but this rate dropped further for disclosure to spouses/partners. Respondents

**Table 2: Disclosure to anyone excluding a health-care professional**

| Variable  | Frequency (%) |
|---|---------------|
| Disclosure to anyone excluding health care professional (n=364) |               |
| Yes   | 298 (81.9)    |
| No  | 66 (18.1)     |
| Total   | 364 (100)     |
| Timing of disclosure (n=298)                                    |               |
| Same day  | 202 (67.8)    |
| Within days   | 25 (8.4)      |
| Within weeks  | 21 (7.0)      |
| After months  | 31 (10.4)     |
| After years   | 19 (6.4)      |
| Total   | 298 (100)     |
| First person disclosed to (n=298)                               |               |
| Family member   | 190 (63.7)    |
| Spouse  | 78 (26.2)     |
| Friend  | 16 (5.4)      |
| Boyfriend   | 8 (2.7)       |
| Religious leader  | 5 (1.7)       |
| Colleague   | 1 (0.3)       |
| Total   | 298 (100)     |
| Disclosure to spouse/sexual partner (n=364)                     |               |
| Yes   | 220 (60.4)    |
| No  | 144 (39.6)    |
| Total   | 364 (100)     |
| Timing of disclosure (n=220)                                    |               |
| Same day  | 149 (67.7)    |
| Within days   | 12 (5.4)      |
| Within weeks  | 14 (6.4)      |
| After months  | 22 (10.0)     |
| After years   | 23 (10.5)     |
| Total   | 220 (100)     |

had various reasons for disclosing their status and received both positive and negative reactions. Knowledge of spouse/partners' HIV status had a positive significant influence on disclosure rates.

It has been shown that though the financial constraints and some sociocultural factors impede adherence, disclosure among other factors actually aids retention in care and treatment of HIV-positive patients.<sup>[21]</sup> Hence, the public health importance of disclosure cannot be overemphasized.

The proportion of the respondents who had disclosed to anyone else apart from a health-care professional is higher than the proportion among HIV-positive Zimbabwean women of whom 55% had disclosed their seropositive status to anyone.<sup>[13]</sup> It is also higher than the 50.9% reported in a similar study in Ogun state, South West Nigeria<sup>[8]</sup> but lower than figures from a recent study carried out in Abakaliki, Southeast Nigeria where 94.6% of respondents had disclosed.<sup>[17]</sup> Similar to findings in South Africa,<sup>[22]</sup> early disclosure was also observed among most respondents (within a month of diagnosis). It appears

**Table 3: Reasons for disclosure or nondisclosure of human immunodeficiency virus-positive status**

| Reasons   | Frequency (%) |
|---|---------------|
| For disclosure to anyone apart from healthcare professional (n=298)   |               |
| Failing health  | 147 (49.3)    |
| Anticipated social support  | 65 (21.8)     |
| Sense of ethical responsibility                                       | 52 (17.4)     |
| To minimize the stress of keeping it secret                           | 38 (12.8)     |
| Other reasons for disclosure  | 23 (7.7)      |
| To prevent transmission to them                                       | 12 (4.0)      |
| For nondisclosure to anyone apart from healthcare professional (n=66) |               |
| Negative public opinion   | 56 (84.8)     |
| Personal secret   | 35 (53.0)     |
| Discrimination  | 28 (42.4)     |
| Fear of rejection and abandonment                                     | 25 (37.9)     |
| Fear of being blamed  | 7 (10.6)      |
| Disruption of family relationships                                    | 7 (10.6)      |
| For disclosure to spouse/sexual partner (n=220)                       |               |
| Sense of responsibility   | 74 (33.6)     |
| Tested together with spouse   | 60 (27.3)     |
| Anticipated partner's support   | 47 (21.4)     |
| Failing health  | 43 (19.5)     |
| To minimize stress of keeping it secret                               | 27 (12.3)     |
| Other reasons for disclosure  | 10 (4.5)      |
| To aid condom use in prevention                                       | 6 (2.7)       |
| For nondisclosure to spouse/sexual partner (n=144)                    |               |
| Fear of losing relationship   | 58 (40.3)     |
| Personal secret   | 24 (16.7)     |
| Other reasons for nondisclosure                                       | 19 (13.2)     |
| Fear of accusation of infidelity                                      | 12 (8.3)      |
| Negative effect on the children                                       | 8 (5.6)       |
| Fear of being blamed  | 7 (4.9)       |
| Loss of financial support   | 4 (2.8)       |
| Fear of physical abuse  | 3 (2.1)       |

\*Multiple responses allowed

disclosure rates have improved over the years. This may be as a result of several global and local efforts to reduce stigmatization associated with HIV/AIDS.

The disclosure rate to spouse/sexual partner observed in this study is higher than that in Ogun state, Southwest Nigeria (50.9%)<sup>[8]</sup> and lower than the findings of a 2010 cross-sectional survey in Southern Ethiopia (85.7%).<sup>[15]</sup> Their sense of responsibility and testing together were the major reasons for disclosing to their spouse/sexual partner. However, then their progressively ailing health and anticipated family and social support made them disclose to other people, especially family members. A similar pattern was also reported in Zimbabwe<sup>[13]</sup> and across Africa.<sup>[23]</sup> This underscores the importance of good understanding of the disease by individuals and family involvement at each stage of care.

**Table 4: Reactions following disclosure of human immunodeficiency virus-positive status**

| Reactions   | Frequency (%) |
|---|---------------|
| From anyone else apart from a health-care professional (n=298)                        |               |
| Positive  |               |
| Acceptance  | 224 (75.2)    |
| Increased support   | 180 (60.4)    |
| Kindness  | 120 (40.3)    |
| Closer relationship   | 24 (8.1)      |
| Decreased anxiety   | 14 (4.7)      |
| Others  | 1 (0.3)       |
| Negative  |               |
| Blame   | 9 (3.0)       |
| Abandonment   | 7 (2.4)       |
| Anger   | 6 (2.0)       |
| Stigma  | 6 (2.0)       |
| Others (denial, loss of support)  | 3 (1.0)       |
| Depression  | 1 (0.3)       |
| From spouse/sexual partner (n=220)  |               |
| Positive  |               |
| Acceptance and kindness   | 159 (72.3)    |
| Increased support   | 132 (60.0)    |
| Better relationship   | 47 (21.4)     |
| Better adherence to medication  | 25 (11.4)     |
| Better participation in PMTCT   | 19 (8.6)      |
| Condom use in HIV prevention  | 16 (7.3)      |
| Opportunities to plan for the future  | 11 (5.0)      |
| Decreased anxiety   | 10 (4.5)      |
| Spouse went for VCT   | 2 (0.9)       |
| Negative  |               |
| Blame   | 15 (6.8)      |
| Anger   | 14 (6.4)      |
| Abandonment   | 13 (5.9)      |
| Other reactions (divorce, strained relationship, "no support because he is negative") | 8 (3.6)       |
| Violence  | 3 (1.4)       |
| Stigma  | 3 (1.4)       |
| Depression  | 1 (0.3)       |

\*Multiple responses allowed. PMTCT=Prevention of mother to child transmission, HIV=Human immunodeficiency virus, VCT=Voluntary counseling and testing

On the other hand, those who did not disclose were afraid of stigmatization and losing their relationships in addition to keeping their personal secret. Fear of stigmatization, abandonment, HIV status being a personal matter, and uncooperative sexual partners are some of the reasons which have been given for nondisclosure in other studies.<sup>[18-24]</sup> Nondisclosure to spouse/partner and other significant family members would likely hinder best prevention practices. It will also likely rob them of the opportunity for prophylaxis in the case of exposure from the victim. Continuous efforts are thereby needed to conquer the stigma attached to HIV/AIDS if we are to achieve zero new infections.

**Table 5: Factors associated with disclosure of human immunodeficiency virus-positive status**

| Variable  | Yes (%)    | No (%)     | Total | $\chi^2$ | P      |
|---|------------|------------|-------|----------|--------|
| <b>Disclosed to anyone else apart from health care professional</b> |            |            |       |          |        |
| Duration of diagnosis (years)                                       |            |            |       |          |        |
| <1  | 68 (70.1)  | 29 (29.9)  | 97    | 18.36    | <0.001 |
| 2-4   | 88 (79.3)  | 23 (20.7)  | 111   |          |        |
| $\geq 5$  | 142 (91.0) | 14 (9.0)   | 156   |          |        |
| Total   | 298        | 66         | 364   |          |        |
| <b>Disclosed to spouse/sexual partner</b>                           |            |            |       |          |        |
| Age group (years)   |            |            |       |          |        |
| 21-30   | 55 (60.4)  | 36 (39.6)  | 91    | 19.88    | <0.001 |
| 31-40   | 117 (68.8) | 53 (31.2)  | 170   |          |        |
| 41-50   | 39 (54.9)  | 32 (45.1)  | 71    |          |        |
| $\geq 50$   | 9 (28.1)   | 23 (71.9)  | 32    |          |        |
| Total   | 220        | 144        | 364   |          |        |
| Aware of spouse/sexual partner's HIV status                         |            |            |       |          |        |
| Yes   | 179 (90.5) | 22 (9.5)   | 201   | 153.72   | <0.001 |
| No  | 41 (29.0)  | 122 (71.0) | 163   |          |        |
| Total   | 220        | 144        | 364   |          |        |
| Religion  |            |            |       |          |        |
| Christianity  | 145 (62.2) | 88 (37.8)  | 233   | 0.87     | 0.351  |
| Islam/others  | 75 (57.3)  | 56 (42.7)  | 131   |          |        |
| Total   | 220        | 144        | 364   |          |        |
| Level of education  |            |            |       |          |        |
| None  | 27 (58.7)  | 19 (41.3)  | 46    | 4.21     | 0.240  |
| Primary   | 38 (50.7)  | 37 (49.3)  | 75    |          |        |
| Secondary   | 114 (64.0) | 64 (36.0)  | 178   |          |        |
| Postsecondary   | 41 (63.1)  | 24 (36.9)  | 65    |          |        |
| Total   | 220        | 144        | 364   |          |        |

HIV=Human immunodeficiency virus

Majority of the respondents who had disclosed to anyone apart from a health-care professional testified to positive experiences of acceptance and increased social support. These findings are similar to those of another study also in Lagos, where 96.7% of those who had disclosed to anyone experienced no negative reactions and had no regrets following disclosure.<sup>[25]</sup> This is encouraging and a pointer to the various HIV-related programs carried out in Lagos State. In Jos, Northern Nigeria (86.9%)<sup>[26]</sup> and Northern Ethiopia (74.5%),<sup>[27]</sup> majority of the women also received acceptance and increased support from their spouses upon disclosure. In contrast to this study, higher rates of negative reactions (20.5%) were reported in Southeast Nigeria.<sup>[17]</sup> Fortunately, few (1.4%) of them experienced physical violence upon disclosure unlike the 30% reported among women in Northern Nigeria,<sup>[28]</sup> and in Uganda, where 29.3% of the respondents reported intimate partner violence following disclosure of seropositive status to their partners.<sup>[29]</sup> This difference may have religious and cultural undertones. Furthermore, a majority of our respondents were married/cohabiting, and many testified

that testing together encouraged them to disclose to their spouses/partners. This may have helped to douse the tension and reduce physical violence.

Significantly higher disclosure rates were seen among respondents who had longer postdiagnosis periods. Most likely, they have more advanced disease and would require more support hence the disclosure. With regard to the significantly higher disclosure rates found among women who knew their spouses'/partners' HIV status, presumably they were also HIV positive, thus making it easier to disclose. Similar to the findings in South Ethiopia and Cape Town, no significant differences in disclosure rates with regard to the level of education or religion were observed.<sup>[15-20]</sup>

### Strengths and weaknesses

This study provides insight into a sensitive issue such as HIV disclosure which is very important in the control of the disease. The roles of duration of diagnosis and knowledge of spouse/partner's HIV status in disclosure were exposed. Findings provide much-needed data to inform program designs in developing countries. Studying women in two treatment centers would not be representative of the state nor country. It would have been better if responses were verified from family members and sexual partners. A qualitative component would also have been beneficial.

### Conclusions

There are high disclosure rates to non health-care professionals but lower rates for spouses/sexual partners. The reactions following disclosure to spouse/sexual partner as well as to other persons were mostly positive. Longer duration post-diagnosis and knowledge of spouse's/sexual partner's HIV status significantly increased disclosure rates.

Male involvement in HIV/AIDS management among women; people living with HIV/AIDS joining support groups; and strengthening of these support groups in all HCT centers are vital. Inclusion of disclosure plans in HIV/AIDS counseling guidelines is also recommended. In addition, HIV/AIDS program should include community-based awareness components which will include information on the importance of disclosure. Larger scale studies are necessary to gain more knowledge on the issues surrounding HIV-positive status disclosure.

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## QUESTIONNAIRE 1

### Determinants and effects of disclosure of HIV status among HIV-positive women accessing care in Lagos Island, Lagos State

This questionnaire is a tool to help collect information regarding the patterns of, reasons for disclosure or nondisclosure and the effects of disclosure among HIV-positive women.

Kindly provide appropriate and accurate responses to the following questions.

Instruction to interviewer: Place a tick (✓) in the box provided on the right side of the options.

#### Section A - Sociodemography

1. AGE at last birthday (please write in the number): \_\_\_\_\_ Years
2. NATIONALITY
  - a. Nigerian
  - b. Non-Nigerian
3. ETHNICITY
  - a. Hausa
  - b. Ibo
  - c. Yoruba
  - d. OthersPlease specify \_\_\_\_\_
4. RELATIONSHIP STATUS
  - a. Never married
  - b. Married/cohabiting
  - c. Divorced/separated/widowed
5. FAMILY TYPE
  - a. Polygamous
  - b. Monogamous
6. RELIGION
  - a. Christian
  - b. Islam
  - c. Others
7. EDUCATIONAL LEVEL
  - a. No formal education
  - b. Primary
  - c. Secondary
  - d. Postsecondary
8. OCCUPATION
  - a. Professional
  - b. Skilled
  - c. Unskilled
  - d. Unemployed
9. NUMBER OF CHILDREN
  - a. 0
  - b. 1
  - c. 3
  - d. 3
  - e. 4
  - f. ≥5
10. ARE YOU LIVING WITH YOUR SPOUSE/SEXUAL PARTNER?
  - a. Yes
  - b. No
11. ARE YOU AWARE OF YOUR SPOUSE'S/SEXUAL PARTNER'S HIV STATUS?
  - a. Yes
  - b. No
12. ARE YOU TAKING MEDICATIONS FOR HIV?
  - a. Yes
  - b. No

#### Section B - Patterns of disclosure

13. HOW LONG HAVE YOU KNOWN OF YOUR HIV STATUS (please write in the number of months or years) \_\_\_\_\_
14. HAVE YOU DISCLOSED YOUR HIV STATUS TO ANYONE EXCLUDING A HEALTH-CARE PROFESSIONAL?
  - a. Yes
  - b. NoIf your response is no, please skip to question 20
15. IF YOUR ANSWER TO QUESTION 14 IS YES, WHO DID YOU DISCLOSE TO FIRST?
  - a. spouse
  - b. Boyfriend/Fiance
  - c. Friend
  - d. Family member
  - e. Colleague
  - f. Religious leader
16. HOW LONG DID IT TAKE YOU TO DISCLOSE TO THE FIRST PERSON AFTER YOU WERE DIAGNOSED?
  - a. The same day
  - b. Days
  - c. Weeks
  - d. Months
  - e. Years
17. HAVE YOU DISCLOSED YOUR HIV STATUS TO YOUR SPOUSE/SEXUAL PARTNER?
  - a. Yes
  - b. NoIf your response is NO, Please go to question 22



18. HOW LONG DID IT TAKE YOU TO DISCLOSE TO YOUR SPOUSE/SEXUAL PARTNER AFTER YOU WERE DIAGNOSED?

- a. The same day  b. Days  c. Weeks  d. Months  e. Years

*Section C – Reasons for disclosure or nondisclosure*

19. IF YOU HAVE DISCLOSED TO ANY PERSON APART FROM A HEALTH CARE PROFESSIONAL, WHAT DO YOU THINK ENCOURAGED YOU TO DO SO?

- a. Anticipated social support  b. Failing health   
c. Sense of ethical responsibility  d. To prevent transmission of the HIV to them   
e. To minimize stress associated with keeping it secret

Other reasons (please specify) \_\_\_\_\_

20. IF YOU HAVE NOT DISCLOSED TO ANYONE APART FROM A HEALTH-CARE PROFESSIONAL, WHAT DO YOU THINK IS PREVENTING YOU FROM DOING SO?

- a. Fear of being blamed  b. Negative public opinion   
f. fear of rejection and abandonment  d. Personal secret   
e. Discrimination  f. disruption of family relationships

Other reasons (please specify) \_\_\_\_\_

21. IF YOU HAVE DISCLOSED TO YOUR SPOUSE/SEXUAL PARTNER, WHAT DO YOU THINK ENCOURAGED YOU TO DO SO ?

- a. Anticipated social support  b. We were tested together   
c. Sense of ethical responsibility  d. Failing health  e. To minimize stress   
f. associated with keeping it secret

Other reasons (please specify) \_\_\_\_\_

22. IF YOU HAVE NOT DISCLOSED TO YOUR SPOUSE/SEXUAL PARTNER, WHAT DO YOU THINK IS PREVENTING YOU FORM DOING SO?

- a. Fear of accusation of infidelity  b. Fear of physical abuse   
c. Fear of losing relationship  d. Fear of being blamed   
e. Negative effect on the children  f. Loss of financial support

g. Personal secret

Other reasons (please specify) \_\_\_\_\_

*Section D – Effects of disclosure*

23. WHAT WAS THE OUTCOME AFTER YOU DISCLOSED TO ANYONE APART FROM YOUR SPOUSE? (You can tick more than one option)

**Positive**

- a. Increased support  b. Acceptance  c. Kindness   
d. Decreased anxiety and depression  e. Closer relationship

**Negative**

- a. Blame  b. Abandonment  c. Anger   
d. violence  e. stigma  f. depression

24. WHAT WAS THE OUTCOME AFTER YOU DISCLOSED TO YOUR SPOUSE/SEXUAL PARTNER? (You can tick more than one option)

**Positive**

- a. Increased support  b. Acceptance and Kindness   
c. Decreased anxiety and depression  d. Better participation in PMTCT   
e. better relationship  f. Condom use for HIV prevention   
g. Increase opportunities to plan for the future carefully   
h. better adherence to use of medications

**Negative**

- a. Blame  b. Abandonment  c. Anger   
d. violence  e. stigma  f. depression

Other (please specify) \_\_\_\_\_

Thank you for your cooperation.