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Predictors and patterns of hiv status disclosure among hiv positive pregnant women at mbarara regional referral hospital, south-western uganda

Abstract

Background: Disclosure of HIV positive serostatus to sexual partners and other persons is useful for prevention and care. One of the contextual factors driving the HIV epidemic in Uganda is non-disclosure. Disclosure of HIV positive serostatus to sexual partners and, or close relatives and friends is a very vital public health strategy as it gives many benefits to the individual and the community.

Study objectives: To determine the predictors, rates, patterns and reasons for disclosure and non-disclosure of HIV sero-positive pregnant women attending antenatal care at Mbarara Regional Referral Hospital.

Methods: This was a cross sectional study done in 2009 using both quantitative employing use of a questionnaire and qualitative methods using Focus Group Discussions. The study was conducted on a group of HIV positive pregnant women attending Mbarara Regional Referral Hospital antenatal clinic.

Results: Out of the 103 respondents, 88 (85.4%) had disclosed their serostatus to at least someone and 57% of these had disclosed to their partners. Of all the respondents, 79.5% had disclosed within less than 2 months of testing HIV positive. Women disclosed their serostatus because their partners had disclosed to them (27.3%), their partners were caring (27.3%) and the health workers had encouraged them to disclose (25.0%). Majority were comforted (73.9%) while others were verbally abused. Reasons for non-disclosure were fear of abandonment (33.3%), being beaten (33.3%) and loss of financial and emotional support (13.3%). The factors associated with disclosure included age 26-35 years (OR 3.9, 95% CI 1.03-15.16), primary education (OR 3.53, 95%CI 1.10-11.307) and urban dwelling (OR 4.22, 95% CI 1.27-14.01).

Conclusion: Majority (85.4%) of the respondents disclosed to at least someone, especially their partners. Majority were comforted and many of them were encouraged by the health workers. Verbal and physical violence were the most important barriers to disclosure. Health workers play a pivotal role in facilitating disclosure and there is need to increase male partner involvement in antenatal care programs.

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Introduction

HIV/AIDS is a major public health problem worldwide and sub-Saharan Africa is the worst hit by the epidemic. About 24.7 million persons were living with HIV and 1.5 million being new HIV infections in 2013 representing 71% of the global burden of the disease yet only 10% of the world's population lives in Africa.[1]

Women are counseled to share with their partner their own HIV test result, and they become responsible for encouraging their partner to undertake HIV testing. The dialogue on sexual activity or HIV/AIDS within a couple is often difficult, especially when women discover that they are HIV-infected.[2] Sixty percent (60%) of HIV positive pregnant women in an antenatal in Dar Es Salaam, Tanzania had not disclosed their results of the HIV test to their partners.[3] Disclosure is a very important component in uptake of PMTCT services.[4]

Disclosure of HIV positive serostatus to sexual partners and, or close relatives and friends is an important public health strategy because it offers a number of benefits to the individual and the community.[5] HIV counselling and testing (HCT) programs as well posttest care services such as antiretroviral therapy (ART) and pre-ART care emphasize HIV serostatus disclosure among people living with HIV/AIDS. Disclosure leads to emotional and psychological support and would also result in partners undertaking HCT. Since disclosure creates the awareness of HIV risk to untested sexual partners, it subsequently leads to greater uptake of HCT.[6]

Disclosure of HIV sero-status of women to their sexual partners supports risk reduction and facilitates access to prevention and care services for people living with HIV/AIDS. Disclosure Is associated with being married, increased condom use, knowledge of partner's HIV sero-status, knowledge of the partner's status, late stage, staying together with partner, discussion about HIV testing before going for testing.[6,7] Having a sexual partner who had also tested, having secondary education and attended more antenatal care visits makes it easier for the woman to disclose her HIV seropositive status.[8] Disclosure is also associated with increased uptake and retention in PMTCT programs.[9]

Self-disclosure of sensitive information is generally thought to have beneficial effects on an individual's health including lowering stress levels, which leads to better psychological and physical health. HIV positive individuals who disclose their serostatus are in a better position to make reproductive choices and have been found to have better psychological support. Disclosure also facilitates behaviors that may improve the management of HIV such as increased

participation in PMTCT programs and improved adherence to ART treatment.[10] Disclosure has negative effects, which include physical violence, separation, abandonment of family responsibilities, and decreased access to resources (food, shelter or finances). Fortunately, the majority of cases reported greater support and understanding from their partners upon disclosure of HIV positive test results.[5] The existing evidence base for interventions to increase disclosure is limited and shows variable results. Further research is needed to determine whether current approaches to increasing disclosure are effective or whether new approaches should be considered.[11]

Therefore this study was done to determine the predictors, patterns, outcomes, rates and reasons for disclosure and non-disclosure of HIV serostatus among HIV positive pregnant women attending antenatal care at a tertiary university teaching and referral hospital in Western Uganda.

Methods

Study site

The study was conducted at Mbarara Regional Referral Hospital Antenatal Care clinic (ANC). Mbarara Hospital is both a teaching hospital for Mbarara University Medical School and Regional Referral Hospital located within Mbarara Municipality, Mbarara district in the Western region of Uganda about 270Km from the Capital City Kampala. It caters for a multiplicity of patients from various ethnic backgrounds speaking many local dialects. Some patients come from as far as the Democratic Republic of Congo, Rwanda and the Northern part of Tanzania. It's a teaching Hospital for Mbarara University medical school.

Study design

The study was a cross sectional study using both quantitative and qualitative methods. The quantitative method involved use of interviewer-administered pre-tested questionnaires while the qualitative method involved two focus group discussions (FGDs) i.e. eight HIV positive women who had disclosed their serostatus and eight positive women who had not disclosed.

Study population

The study was conducted on a group of HIV positive pregnant women attending Mbarara Regional Referral Hospital ANC.

Sampling procedure

The HIV positive pregnant women attending MRRH ANC were consecutively recruited until the desired number of 103 was achieved while every 5th respondent during the quantitative survey was also requested to participate in a focus group discussion until the required number of eight participants per group.

Sample size

The sample size was 103 as calculated from the formula by Kish and Leslie (1965).

Data collection and instrument

The HIV positive mothers were received at the registration desk with the rest of the pregnant women. They were identified by their HIV status codes on their ANC charts. The HIV positive women were thus identified and an attendant clinician in a room specifically meant for them individually saw each of the HIV positive women.

Quantitative data was collected using interviewer-administered pre-coded pre-tested questionnaires to determine: The socio-demographic variables such as age, marital status, residence, employment, education level, nature of domicile, religion, parity, and tribe. The disclosure status-whether disclosed or not, to whom, when, outcomes of disclosure. The primary outcome was disclosure.

Quality control

The questionnaire was pre-tested and translation double verified. The questionnaire was piloted and necessary adjustments made. The data was cleaned. During the focus group discussions, the interview was recorded using a voice recorder.

Data entry and analysis

Quantitative data was entered into the EPI-INFO program and analyzed using the statistical package for social science (SPSS version 12). The categorical data was summarized into frequencies or proportions. The socio-demographic characteristics of women who disclosed their HIV serostatus were analyzed. Significance of association between social, economic and demographic categorical variables with disclosure status was obtained using binary logistical regression analysis and an association was considered significant at p-value less than 0.05. The qualitative data was verbatim transcripted, categories created with evidences from the responses and coded using the thematic content analysis.

Ethical consideration

The work was presented to the department of obstetrics and Gynecology at Mbarara University and ethical approval sought from the faculty research ethical committee.

Results

Majority of the participants were between the ages of 18 and 35 years (94.2%), Christians (89.3%), had primary education (56.3%), were married either monogamously or polygamously (94.1%), were multipara (61.2%), lived in a nuclear family setting (71.8%), unemployed (59.2%) and had a monthly income of between 50,000-100,000 Uganda shillings (42.7%).Of the respondents who were below 18 years, 83.3% had disclosed their serostatus. Disclosed among those who had no formal education was 100% (Table 1).

Table 1 The Socio-demographic characteristics in relation to disclosure

Variables	Frequency (%) N=103 (100%)	Disclosed (N=88)
Age		
Below 18	6(5.8)	5(83.3%)
18-25	51(49.5)	40(78.4%)
26-35	46(44.7)	43(93.5%)
Religion		
Catholic	40(38.8)	32(80.0%)
Anglican	49(47.6)	44(89.8%)
Pentecostal	3(2.9)	1(33.3%)
Moslem	11(10.7)	11(100%)
Education level		
No formal	5(4.9)	5(100%)
Primary	58(56.3)	53(91.4%)
Secondary	35(34.0)	27(77.1%)
Tertiary	5(4.9)	3(60.0%)
Marital Status		
Single	3(2.9)	2(66.7%)

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Table Continued...

Variables	Frequency (%) N=103 (100%)	Disclosed (N=88)
Married monogamously	67(65.0)	57(85.1%)
Married polygamously	30(29.1)	27(90%)
Divorced/Separated	2(1.9)	2(100%)
Widowed	1(1.0)	0(0.0%)
Parity		
Prime gravida	32(31.0)	26(81.2%)
Multipara (2-4)	63(61.2)	55(87.3%)
Grand multipara (5 or more)	8(7.8)	7(87.5%)
Domicile		
Nuclear family	74(71.8)	62(83.8%)
Extended family	29(28.2)	26(89.7%)
Residence		
Urban	85(82.5)	44(91.7%)
Rural	18(17.5)	44(80.0%)
Patient Employment		
Unemployed	61(59.2)	53(86.9%)
Informal sector	37(33.0)	29(85.3%)
Formal/skilled	18(7.8)	6(75.0%)
Monthly Income		
Less than 50,000	29(28.2)	25(86.2%)
50,000-100,000	44(42.7)	39(88.6%)
More than 100,000	30(29.1)	24(80.0%)

Persons disclosed to included partners (57%), parents (25%), friends (9%), relatives (6%) and siblings (3%) (Table 2). Out of the 103 respondents, 88 (85.4%) had disclosed to at least someone. About seventy nine percent (79%) had disclosed within less than 2 months of testing positive while 9.1% had disclosed after 6 or more months of having tested positive.

Table 2 The timing of disclosure

Variable	Frequency (percent %) N (%)
Disclosure status	
Yes	88 (85.4)
No	15 (14.6)
Disclosure timing	
Less than 2months	70 (79.5)
2-5months	10 (11.4)
6 or more months	8 (9.1)

One of the respondents in the focus group discussions reported having disclosed within seven days as evidenced by her response i.e. "*I told my husband on the second day following my testing positive because he had disclosed to me his serostatus and was openly taking his HIV drugs*" said 30year old mother of three (Table 3). Most women who disclosed their sero-status were encouraged by health care workers, had partners who were caring and had disclosed to them.

Table 3 Factors that motivated disclosure (N=88)

Factors Motivating Disclosure	Frequency (Percent %)
He had disclosed to me	24 (27.3)
He was caring	24 (27.3)
I was financially stable	7 (8.0)
Wanted safer sex	11 (12.5)
Encouraged by health worker	22 (25.0)

This was further supported by information gathered from the focus group discussions where participants reportedly disclosed because their partners had disclosed to them and some had been encouraged to do so by the health workers as said by participants a 32 year mother of four children and 22 year a primipara respectively:

"*I told my husband on the second day following my testing positive because he had disclosed to me his serostatus and was openly taking his HIV drugs*". "*The health worker always reminded and encouraged me whenever we met and I got the boldness to tell my husband*"

Post disclosure experiences

Majority were comforted (73.9%), others were accused of infidelity (24.9%), others were verbally abused (6.8%), some were beaten (5.7%), and a few were actually chased out their homes by their husbands and the relatives of their husbands (2.3%). The information from the focus group discussions lent further credence to that gathered from the questionnaires with respondents reporting increased support and comforting as said by a 25 year old mother of 3:

"*When I told my mother that I was HIV positive, she was so sad but later comforted me and promised to give me all the support I needed*".

She had also told her partner-"*My partner pledged his support and continued love till death do us part. He has always reminded me to take my drugs and goes with me to hospital during my clinic days*".

Others reported financial loss, being beaten, sex denial, divorce and stigma as some of the outcomes of their having disclosed their serostatus. Some of their responses included the following i.e.

"*When I told my partner, he beat me that night and locked me in the house for two days though he came back to his senses and stopped harassing me*" reported 18 year old primipara (Table 4).

Table 4 The relationship between social demographic characteristics and disclosure

Variable	Standard Error(SE)	Odds Ratio (95%CI)	P-value
Age			
Less than 18	1.25	2.9(0.25-33.07)	0.40
26-35	0.69	3.9(1.03-15.16)	0.05
18-25	0	0	0
Education			
No formal or Primary education	0.60	3.53(1.10-11.307)	0.03
Post primary	0	0	0
Religion			
Anglican	0.62	0.46(0.136-1.52)	0.20
Others (Moslem, Pentecostal)	0.86	0.67(0.124-3.60)	0.64
Catholics	0	0	0
Marital Status			
Married polygamously	0.70	0.63(0.16-2.49)	0.51
Other marital status	0.93	2.85(0.46-17.69)	0.26
Married monogamously	0	0	0
Parity			
Prime Gravida	0.58	0.63(0.20-1.95)	0.41
Multi para	0	0	0
Domicile			
Nuclear	0.69	0.50(0.16-2.30)	0.45
Extended	0	0	0
Residence			
Urban	0.61	4.22(1.27-14.01)	0.02
Rural	O	0	0

Table Continued...

Variable	Standard Error(SE)	Odds Ratio (95%CI)	P-value
Patient Employment			
Unemployed	0.62	1.14(0.34-3.81)	0.83
Informal	0.90	2.21(0.38-12.90)	0.38
Formal	0	0	0
Spouse employment			
Unemployed	085	1.90(0.34-3.81)	0.45
Informal	0.85	4.33(0.38-12.89)	0.86
Formal	0	0	0
Monthly Income			
More than 100,000shs	0.72	0.80(0.20-3.27)	0.76
50,000-100,000	0.71	1.56(040-6.23)	0.53
Less than 50,000	0	0	0
ANC Visits			
4 or more	0.57	1.14(0.37-3.48)	0.82
Less than 4	0	0	0

The factors associated with disclosure were age between 26-35 years (OR 3.9, 95% CI 1.03-15.16), primary education (OR 3.53, 95%CI 1.10-11.307) and urban dwelling (OR 4.22, 95% CI 1.27-14.01). Reasons for non-disclosure included fear of abandonment (32%), being beaten (32%), loss of financial support (12%), stigmatization (12%), loss of emotional support (6.7%), and others thought that disclosure was not necessary (6.7%).

The above information from the questionnaires was supported by information gathered from the focus group discussions where women reported fear of death, divorce, being beaten, job denial and ignorance of the importance of disclosure were reported as some of the barriers to disclosure. Some of the responses included the following i.e.

"*Knowing that he easily gets upset by small things and begins fighting, if I tell him about my status will he not beat me to death? His brother beat his wife seriously when he found that she was positive and he is now in prison*" said 29 year primary school teacher.

"*Can't I live with my disease without bothering people by telling them of my issues? In feel comfortable that way*" reported a 40 year old prisons warder and a mother of 6 children.

"*I am looking for a job right now and if probable employers get to know that am positive, they may deny me a job. I will reveal my status when I have a job*" reported a 34 year old mother of 3 children.

Reaction when upon disclosure: The majority of the women reported that they were indifferent (38.0%), others comforted their partners (22.0%), 12.0% were disappointed, 16.0% were got the courage to go and test and find their status and12.0% were happy that their husbands were HIV positive.

Discussion

Rates and patterns of disclosure

The percentage of disclosure by the women in this study was 85.4% and the majority had disclosed to their partners (56.8%). A study in Dar Es salaam, Tanzania in an ANC clinic interviewing HIV positive women about disclosure to their partners found that 69% had disclosed to their partners.[5] Among 104 HIV seropositive pregnant women enrolled in a Nairobi antenatal setting, 65% reported informing their partners of their serostatus. The overall HIV status disclosure to sexual partner in a study in Ethiopia was 57.4% and the study showed that there is significant association between knowing HIV status of sexual partner. These rates of disclosure to partners are almost similar probably because the settings were almost the same and the populations studied were from the low resource settings and probably had similar socio-economic and demographic characteristics.

Factors facilitating disclosure

Disclosure to spouse was facilitated by partner having disclosed their status first, partner being caring, encouragement by the health worker. Some disclosed because they wanted to practice safer sex. Because of the complexity and ongoing nature of HIV-infected women's struggle with disclosure issues, counseling support and encouragement from health workers is critical to help these women realistically appraise their concerns related to disclosure so that they can access needed support and services. The men who undergo testing for HIV should also be encouraged to disclose their status to their partners so that counter disclosure can occur and care sought at the earliest opportunity.

Barriers to disclosure

Medley documented women's experience of disclosure to their partner and reported the barriers to disclosure as women's fears related to stigmatization, family rejection, breach of confidentiality, or accusations of infidelity. Similarly, a small group of women (15.6%) had not disclosed their status to anyone. These women feared abandonment, being beaten, loss of financial support, stigmatization, loss of emotional support, and others did not know the importance of disclosure. This group of women considered the disclosure process to be too difficult and risky to undertake and engaged in avoidant behaviors to hide their HIV status. Some of them kept taking their medications in hiding; others would only go to the HIV clinics only when their partners were not near.[10]

Men and women who did not disclose their HIV status to their sexual partners also did not practice safer sex, especially condom use.[12] Hence, the group of women in this study who did not disclose may be more likely to have re-infection.

Negative disclosure outcomes

Medley revealed a number of potential risks from disclosure for HIV-infected women, including loss of economic support, blame, abandonment, physical and emotional abuse, discrimination and disruption of family relationships. Comparably, women who disclosed were accused of infidelity, others were verbally abused, beaten, and a few were actually chased out their homes by their husbands and the relatives of their husbands. The negative outcomes may lead women to choose not to share their HIV test results with their friends, family and sexual partners. This, in turn, leads to lost opportunities for the prevention of new infections and for the ability of these women to access appropriate treatment, care and support services where they are available.

There is heightened need to emphasize the importance of disclosure so as to enable increased participation in treatment and support programmes; but not forget the negative outcomes of disclosure.

Positive disclosure outcomes

Disclosure of HIV status expands the awareness of HIV risk to untested partners, which can lead to greater uptake of voluntary HIV testing and counseling and changes in HIV risk behaviors. In addition, disclosure of HIV status to sexual partners enables couples to make informed reproductive health choices that may ultimately lower the

number of unintended pregnancies among HIV-positive women.[10] Among women, who disclose their HIV serostatus to their families, friends and sex partners, the incidence of regret was minimal and that disclosure improved on relationship satisfaction and security.[13]

The majority of women who disclosed their HIV sero-status were comforted and now able to participate in HIV treatment programs. Disclosure is necessary to initiate discussions about HIV/AIDS and this raises each partner's awareness of the risk of infection and may ultimately lead to behavior change to reduce risk reduction. Disclosure can be an important starting point for HIV positive women to begin discussing the use of contraception with their partners and reduce the number of unintended pregnancies among HIV infected women. Disclosure helps in women's uptake of PMTCT programmes and in their participation in treatment and support programmes. In order to benefit from interventions that can reduce HIV perinatal transmission, women who are HIV infected must be willing to accept and adhere to PMTCT prophylaxis. The optimal uptake and adherence to PMTCT programmes is difficult for women whose partners are either unaware or not supportive of their participation.

It is well documented in Africa that women often lack the power to make independent decisions with regard to their own health care. It is therefore difficult for HIV infected women to seek social and medical support from care and treatment programmes for themselves and their infants without first disclosing their HIV serostatus to their partners.[14]

Predictors of disclosure

The urban dwellers were more likely to disclose compared to those ones in the rural areas (OR 4.22, 95% CI 1.27-14.01). This could probably be due to the fact that those in the urban areas can access information much easier compared to the people living in the rural areas. Those between 26-35 years were more likely to disclose than those who were between 18-25 years (OR 3.9, 95% CI 1.03-15.16). This could possibly be because those who are older than 25 years are more likely to have spent a longer time in relationships and thus built trust over time resulting into a higher chance to have disclosed compared to the younger ones. The older women are more likely to have gotten pregnant more times than those younger than 26years and this could have exposed them to more information about disclosure leading to their being more likely to disclose.

This compares with the disclosure rate in a case-control study done in Mityana, Uganda comparing 139 people living with HIV/AIDS (PHAs) who had disclosed to 139 PHAs who had not disclosed regarding their socio-demographic characteristics, their experiences and perceptions about disclosure; whereby respondents who were over 25 years were more likely to disclose than those below 25 years. The independent factors that favored disclosure included not fearing negative outcomes of disclosure, having communication skills to disclose, having initiated anti-retroviral therapy, receiving ongoing counselling and having ever seen a PHA publicly disclose his/her HIV status.[15] In a study in Barbados, women who disclosed their HIV status were more likely to be younger than 25 years of age (77.5%), more likely to be married (22.5%) and more likely to be employed (35%) as compared to those women who did not disclose.[16] There could be a similarity probably because the respondents were both HIV positive and living in the third world.

Conclusion

The findings in this study over-emphasize the need for women to be economically empowered so that they don't solely depend on the mercies of their spouses and the importance of the male partner involvement in antenatal care so that the men, who are the bread winners in many families, can get to know the importance of testing together as a couple and their role towards their pregnant women.

Acknowledgments

None.

Conflicts of interest

None.

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