

## **Psychological Trauma Following Disclosure of HIV Status to Significant Others in Women Living With HIV and AIDS**

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### **ABSTRACT**

The impact of HIV and AIDS among African women has been devastating. Since the beginning of the epidemic, over 100,000 cases of AIDS have been reported among women, and 57% of these cases were among African women. New infections among women are increasing at a faster rate than new infections among men. In sub-Saharan Africa, HIV positive women outnumbered HIV positive men. Gender inequalities in personal relationships, in the community, within the workforce, and in political circles affect women all over the world. Inequalities increase women's vulnerability to poverty and vice-versa: both impact harshly on their ability to enjoy full human rights.

The research examined Psychological trauma women experienced following their HIV status disclosure to significant others. The study adopted descriptive qualitative method utilizing semi-structured interviews and focus group discussions (FGDs) as data collection methods. The study was conducted at the President's Emergency Plan for AIDS Relief (PEPFAR), University College Hospital Ibadan. Because of the nature of the study, eighteen participants, all outpatient women of different categories were selected using purposive sampling. Only women who have experienced various negative consequences after disclosure of their HIV status participated in the study.

Findings revealed various negative consequences experienced by the participants after disclosing their HIV status to significant others. Three out of the eight married participants representing 37.5 % of married participants and 16.7% of the overall participants reported being sent away from their marriage by their husbands following disclosure of their HIV status. Three participants representing 16.7 % were relieved of their jobs because of their HIV status, 8 participants representing 44.4% reported various forms of verbal abuses from close friends, family members or health workers and 4 representing 22.2% faced family rejection following the disclosure of their HIV status. Further probing revealed that these women reported various type of psychological trauma, ranging from; regret for disclosing their status, worries about further stigmatization from those who may learn about their HIV status, low self esteem, and social withdrawer. Some have become economically grounded because of loss of jobs or withdrawal of social supports by love ones due to the disclosure of their HIV status.

From the findings of this study, it becomes clear that stigma and discrimination, rejection, isolation and other negative consequences may result from disclosing HIV status to significant others especially in women living with HIV & AIDS. This has impacted negatively on the efforts at curtailing the spread of the disease, getting people to know their status and in adherence to treatment regimen. However, disclosure of HIV positive status can result in negative consequences such as mentioned above, it is widely recognized that PLWHAs could still benefit from disclosure and the participants in this study though regretted the consequences that followed their disclosure, they encourage others to disclose their status.

From these results, it is expedient to promote or design intervention and education programmes that can convey information to people at various levels on the need to stop the stigma and discrimination and other negative emotions that are currently being melted on people living with HIV & AIDS. Furthermore, it becomes important that psychologists should put more efforts at improving the Psychological wellbeing of people living with HIV & AIDS who may also be suffering from Psychological trauma following disclosure of their status. Appropriate Psychological interventions should be designed to ameliorate their suffering. Nigeria Government should formulate relevant laws that will protect People living with HIV & AIDS from abuses.

**Key word:** Psychological Trauma, Disclosure, HIV Status, Significant Others, Psychological intervention.

## 1. INTRODUCTION

Globally, over 7000 people become infected with HIV every day, and more than 33 million are living with HIV (UNAIDS/WHO, 2007; UNAIDS/WHO, 2009). Sub-Saharan Africa is the most affected region. Nearly 70% of all People Living with HIV (PLWHAs) worldwide live in this region, and the majority of these are among 15 – 49 year olds, with nearly 50% occurring among 15–24 year olds (UNAIDS/WHO, 2007; UNAIDS/WHO, 2009). In Nigeria, First case of HIV/AIDS was reported in 1986. In 2010, HIV prevalence is highest in urban areas, the North Central zone, Benue State and among the 30-34 years age group. HIV prevalence among youth age 15-24 declined from 6% in 2001 to 4.3% in 2005, 4.2% in 2008 and 4.1% in 2010, (HSS, 2010). More than 80% of HIV transmission in Nigeria is through heterosexual sex. The drivers of the epidemic in Nigeria include high illiteracy, high rates of Sexually Transmitted Infections (STIs) in vulnerable groups, poverty, low condom use and general lack of perceived personal risk. (NACA factsheet, 2011).

The impact of HIV and AIDS among African women has been devastating. Since the beginning of the epidemic, over 100,000 cases of AIDS have been reported among women, and 57% of these cases were among African American women (Centers for Disease Control and Prevention [CDC], 2000). New infections among women are increasing at a faster rate than new infections among men. In sub-Saharan Africa HIV positive women outnumbered HIV positive men (UNAIDS 2003). Gender inequalities in personal relationships, in the community, within the workforce, and in political circles affect women all over the world. Inequalities increase women's vulnerability to poverty and vice-versa: both impacts harshly on their ability to enjoy full human rights. Gender inequality and poverty not only increase the risk of HIV but also leave women more vulnerable than men to its impact. Short-term survival needs force women to develop a range of coping strategies with varying implications for their long-term health and well-being (UNAIDS 2003).

One of the most important decisions anyone tested to HIV can make is disclosure of status to significant individuals in their lives. However, disclosure needs to be properly handled in order to avoid negative consequences it may engender. Factors to be considered before disclosure is done could include; who to disclose to, when to disclose and how to disclose. Disclosure to a significant person especially a sexual partner is also considered one of the important aspects of combating the spread of HIV especially among sexually active individuals. Counsellors or clinicians discuss with the clients the advantages and disadvantages of disclosure, various options of disclosure, and the timing of disclosure. It is however up to the client to decide to disclose his/her HIV status. It is also up to the client to decide when and how to do it (Paxton, 2002). HIV status disclosure is recognized as an important public health strategy for HIV prevention, as well as care and support. Disclosure helps PLWHAs mainly in terms of supporting their physical, emotional and spiritual health – thus allowing them to continue to live productively and positively with HIV and access HIV-related health care resources. Disclosure could however bring diverse consequences due to negative orientation about HIV & AIDS some of which may be positive or negative. Disclosure that brings positive outcome decreases anxiety and increases social supports among PLWHAs (Matthews, 1999; Cline and Boyd, 1993 in Sowell et al., 2003). In addition according to Paxton (2002), disclosure liberates PLHIV from the burden of secrecy and shame. This in turn facilitates the initiation of HIV treatment and medications (Klitzman, 2004 in UCSF, 2007) and leads to greater acceptance and adherence to HIV treatment (Waddell & Messeri, 2006; Stirratt et al., 2006 in UCSF, 2007)

Notwithstanding the potential benefits of disclosure in terms of care and support for PLWHAs, and for HIV prevention in the general public, disclosure of HIV positive status is often difficult and a potentially risky endeavour. For example, it has been established that in cultures where more traditional values associated with gender roles is emphasized, it may be difficult to tolerate a female HIV-positive member (Ichikawa & Natpratan, 2006). A woman may have similar needs to a man's, but if she gets infected, she is treated as if she is a cursed and dirty being. She is not even given the chance to explain how she got infected. What is most touching about the women is how difficult it is for them to manage their condition once people learn that they are HIV positive. They are disrespected, and shunned even by their own families. (Global Fund, undated)' a case is presented below;

'For instance the case of a woman was reported who is married with nine children. Her husband is a taxi driver and HIV positive and he has infected her with HIV. Her husband had discovered his HIV+ status much earlier and had been receiving medical attention in hospital for a long time, and yet had not told her! Much later when she learned and

informed him about her HIV positive status, instead of telling her the truth, he blamed her for being responsible for the infection and kicked her out of the house! (Global Fund, undated),

This is one of the several challenges some HIV positive women face after their status are being made known to people they consider as significant in their lives.

## **2. THE STUDY**

Studies have shown that disclosure of HIV positive status could be a pivotal factor in reducing the behaviours that continue to transmit the HIV (Marks, Richardson & Maldonado, 1991 in (Serovich, 2001). It is also acknowledged that disclosure of HIV positive status is important for the acquisition of social support (especially from family members) necessary for patients' adherence to treatment (Matthews, Kuhn, Fransman, Hussey & Dikweni, 1999, Waddell & Messeri, 2006). Although disclosure of HIV positive status is important and PLWHAs in Nigeria and elsewhere are often advised to disclose their status, there are always barriers and consequences associated with such disclosure. This study therefore aimed to explore the psychological trauma following disclosure of HIV status to significant others in women living with HIV and AIDS

## **3. METHODS**

### **3.1 Study design**

This was a descriptive qualitative study utilising semi-structured interviews and focus group discussions (FGDs) as data collection methods. This methods were adopted since the aim of the study was to investigate consequences of women disclosing their HIV status to significant others, which demands that a qualitative method suitable for understanding individuals' perceptions and experiences should be adopted.

### **3.2. Study setting**

The study was conducted at the President's Emergency Plan for AIDS Relief (PEPFAR); University College Hospital Ibadan after due ethical approval has been secured from the ethical board of the clinic. The centre is a comprehensive centre for the treatment and management of HIV condition which caters for more than fifteen thousand people living with HIV & AIDS (PLWHAs) that mostly come from the western region of Nigeria

### **3.3. Study population, procedure and sample size.**

Study participants were PLWHAs accessing treatment and care from President's Emergency Plan for AIDS Relief, (PEPFAR), University College Hospital Ibadan. Participants were drawn from those who have been accessing care for more than six months who have disclosed their status to significant persons in their lives. Because of the nature of the study, eighteen participants all outpatient women of different categories were selected using purposive sampling. Only those who had experience to share about the consequences that followed the disclosure of their status participated in the study. There were three categories of women involved in the study. They are; young women between the ages of 18-24, women age 25 - 40 with high socio-economic status and women age 25 - 40 with low socio economic status. Each group were met in different days. The participants willingly participated in the study and each of them signed written consent. Out of the 18 participants, 8 are currently married, 5 are single while 5 are separated from their partners. 12 of the participants have post secondary education while the others have secondary education.

## **4. RESULTS**

All the participants were HIV positive, currently on medication and have all disclosed their status to either their husbands, parents, employers or close friends. Reasons for disclosure were accessed in participants; six participants representing 33.3% disclosed because they needed to start HIV treatment and the information and counselling they had received from health workers had some influence on their decision to disclose. Besides, four participants representing 22.2% of the participants decided to disclose because keeping an HIV positive status a secret was emotionally stressful and worrisome for them, five participants representing 27.7% of the participants disclosed because of the need for support as they were sick at the point of entry while 3 representing 16.3% did not directly disclosed but their status were accidentally known.

Findings from the FGD revealed various negative consequences associated with disclosure of HIV status as reported by the participants. Three out of the eight married participants representing 37.5 % of married participants and 16.7% of the overall participants reported being sent away from their marriage by their husbands following disclosure of their

status. Three participants representing 16.7 % reported loss of job due to their employer's perceived interference of HIV management with their job commitments, eight participants representing 44.4 %, reported various forms of verbal abuses from either close friends, family members or clinic staff and four, representing 22.2% faced family rejection following the disclosure of their HIV status.

Further probing of the effects of disclosure of HIV status by these respondents revealed various forms of psychological traumas ranging from regret for disclosing, worries about further stigmatization from those who may learn about their HIV status, low self-esteem, and social withdrawal from friends and family who became unfriendly and nasty after learning about their status. Some have become economically grounded because of loss of jobs or withdrawal of socio/economic supports due to their HIV status.

## **5. DISCUSSION**

The study has found that issue of disclosure of HIV status to significant others is still a serious decision to be made because of the negative consequences that some people might face following disclosure of their status. Some of the consequences of disclosure reported by participants include; experience of stigma and discrimination, separation from marriage, rejection by friends or family members. Others include; loss of job or loss of financial or social supports from relations or close friends. The resultant effects of these consequences are feeling of psychological trauma which has far reaching effect of the health status of the individuals involved.

## **6. CONCLUSION**

From the findings of this study, it becomes clear that those who disclose their HIV status has various negative experience such as stigma and discrimination, rejection, isolation and other negative consequences which could constitute barriers to secondary prevention efforts and adherence to treatment especially amongst women who tested positive to HIV. It could also discourage people from knowing their status, disclosing it or accessing care and treatment due to fear of being stigmatized or discriminated against. It promotes the spread of the disease especially among married women who may not want to disclosed their status to their husbands because of possible fear of been sent away from their matrimonial homes. However, disclosure of HIV positive status can result in negative consequences such as mentioned above, it is widely recognized that PLWHAs could still benefit from disclosure. Specifically, it is believed that individuals to whom one chooses to disclose could serve as a source of emotional, moral or financial support (Matthews et al., 1999; Brou, 2007). In addition, benefits such as the reduced incidence of HIV infection, willingness to access care and adherence to treatment can potentially be increased by supporting and increasing the number of PLWHAs who are comfortable disclosing their status.

## **7. RECOMMENDATION**

From the finding from this study, it is expedient for health professionals to design intervention and education programmes to convey information to individuals at varied levels (i.e. both at individual and community level) to reduce the stigma and discrimination that is currently attached to HIV/AIDS. One of the consequences of disclosure mentioned by the participants in this study included; ejection from matrimonial homes by the husbands of some of those that are married, this has brought to the fore the need to address gender inequality in the efforts at reducing HIV-related stigma and discrimination. This is particularly necessary if women must be protected from experiencing unnecessary psychological trauma because of HIV which may make them become more vulnerable to other health problems. Counsellors and Clinicians should take the issue of status disclosure by clients more seriously. Counselling on how clients should handle the disclosure of their HIV status should form significant aspect of patient counseling and they should begin to anticipate negative consequences that could follow status disclosure which they must also begin to prepare for. Also, individuals and communities should be sensitized about the need to show complete acceptance, care and support to PLWHAs. This could be done through public enlightenment programmes that will appeal to the emotions of people to showing supports to PLWHAs.

Finally, it becomes important that psychologists should put more efforts at improving the Psychological wellbeing of people living with HIV&AIDS who may also be suffering from Psychological trauma because of their status. Appropriate Psychological interventions should be designed to ameliorate their suffering and government of Nigeria at all levels should formulate relevant laws that will protect People living with HIV & AIDS from abuses.

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