

Barriers to HIV Positive Status Disclosure among Spouses in Kibera Slum, Nairobi County; Kenya

Winfred Mbula Nzioka¹, Dr. Dennis Nyongesa Wamalwa, PhD², John Oduor Ondiege³

¹MSc Candidate, in Health Systems Management, Kenya Methodist University – Kenya, BA in Psychology, Egerton University – Kenya, Diploma in Nursing (KRCHN)-Kenya

²Lecturer / Consultant; Ph.D., Department of Peace and Conflict Studies, Masinde Muliro University of Science and Technology, Kenya, MA Counselling Studies, University of Manchester UK.

³MSc Candidate, in Health Systems Management, Kenya Methodist University – Kenya, BSc Prosthetist and Orthotist, Tumaini University -Tanzania

Abstract- This study aimed to explore the reasons underlying the barriers to disclosing positive status to spouses among people with HIV infection. This was a qualitative exploratory study where 12 respondents participated in the study which had one focus group discussion of 6 members who had disclosed their HIV positive status to their spouses and individual sessions for the 6 members who had not disclosed their status to spouses. They were purposively recruited from 6 deferent post- test clubs they attended within Kibera informal settlement and who were all receiving health care services at MSF Belgium based facilities in Kibera informal settlement. Both one on one and FGD sessions were audiotaped recorded with permission from participants and were verbatim transcribed. Data was analyzed qualitatively by thematic analysis technique. Five major themes emerged from the data; fear of abandonment, fear of rejection/ discrimination, fear of violence, fear of upsetting family members and fear of accusation of infidelity. The study recommended that ongoing Counselling and HIV support groups through post-test clubs may present a key opportunity for discussing fears and concerns around disclosure as well as sharing disclosure strategies amongst peers.

I. INTRODUCTION

UNAIDS (2015) noted that in 35% of countries with available data, over 50% of people reported having discriminatory attitudes towards people living with HIV infection (PLWH). HIV-related stigma and discrimination refers to prejudice, negative attitudes and abuse directed at people living with HIV and AIDS. According to WHO, (2011) and UNAIDS, (2014), it is against such background that fear of stigma and discrimination is known as the main reason for HIV-infected people not to disclose their HIV status and take antiretroviral treatment. (Sayles et al, Wong, Kinsler, Martins, & Cunningham (2009) reported that HIV-infected people who reported experiencing high levels of stigma were over four times more likely to report poor access to care. Stigma and discrimination can prevent HIV-infected people from disclosing their status after finding out they were HIV positive. The disclosure of HIV status among people who test positive for HIV has important implications for preventing new HIV infections and for the treatment, care and support of PLWH. Literature on HIV status disclosure among PLWH is dominated by research on the rates, barriers and consequences

of disclosure to sexual partners, because of the assumed preventive health benefits of partner disclosure (Maman, Rooyenb, & Groves, 2013).

There are some benefits gained by PLWH when they disclose their HIV status, especially to family members. Disclosure of HIV status can lead to increased social support, improved access to treatment, and prevent further HIV- related transmission and related complications. However, several negative effects of HIV status disclosure such as stigma, discrimination, and violence, seem to remain as the main factors for PLWH not disclosing their HIV status (Maman *et al.* 2013).

A deep understanding of the main reasons and factors associated with HIV status disclosure from the perspective of PLWH is important to address the proper interventions of prevention, care, and support for PLWH. This study aims to investigate the barriers faced by PLWH who had and those who were struggling with disclosure of their HIV status to family members

A common example of the way these beliefs inhibit people's adjustment is their reactions to an HIV positive diagnosis. A couple we had done diagnostic counseling and testing within one of the health centers reacted....

"...This can't be true, it can't be me, look unless I got it from the Bible, am a pastor, look at my wife, she is faithful and she was the first woman I had in bed, what are you telling us..."

The prevalent view of the community, although diminishing with increased public knowledge and awareness of HIV/AIDS remains a challenge as De Rosa, and Marks, (1998) puts it: "HIV positive" equals "AIDS" equals "imminent death". This belief is often held by those diagnosed with HIV, and their families, and often results in an emotional paralysis and inability to make plans for the future. It is only when these beliefs are challenged and start to change that they begin living with HIV and rebuild a future self. This will only happen if the counsellor has a good relationship with the client in the counselling session. "A non- blaming, respectful

counselling model which seeks to empower clients to feel in control of their lives and futures may assist people living with HIV/AIDS to live more meaningful lives in general and with their significant others” asserts Stynes (2009)

II. STATEMENT OF THE PROBLEM

Staff, who worked in MSF- Belgium HIV clinics in Kibera informal settlements, reported that HIV-status-disclosure among sexual partners was a major challenge in the effort to fight the spreading of HIV/AIDS, as secrecy led to a lack of adherence to medication.

The benefits of disclosure, however, were observed as being highly therapeutic for the patients. This research therefore sought to explore the barriers to HIV positive status disclosure to spouses in Kibera slum Nairobi County.

III. LITERATURE REVIEW

In the studies that were done above, the barriers were assessed in two ways. Participants were asked directly about the perceived barriers or through multivariate analysis. Barriers were primarily described for disclosure to sexual partners and to a lesser degree, disclosure to other categories of recipient including family, friends and others.

The most common barriers to disclosure that were mentioned by participants included fear of abandonment, fear of rejection/ discrimination, fear of violence, fear of upsetting family members and fear of accusation of infidelity. Those factors assessed through multivariate include ethnicity, severity of disease, age and education.

In exploring these factors, it was important to keep in mind the context in which the participants were offered HIV testing. Therefore, the barriers that different people face when deciding whether or not to share results with their sexual partners may be more extensive including but not limited to;

Fear of abandonment

Fear of abandonment was the major barrier that was mentioned most often by participants from studies both in the developed and developing world. For studies among women, particularly in developing countries, fear of abandonment was closely tied to fear of loss of economic support from partners was reported in 13 of the 14 studies conducted (Simon *et al* 1995). However, a study by Antelman *et al* (2001) conducted in the United Republic of Tanzania did not support this hypothesis that women who are more economically dependent on their partner are less likely to disclose.

Stigma and Discrimination

According to UNAIDS 2004, HIV/AIDS related stigma remains one of the greatest obstacles to people living with HIV being able to fulfil their human rights. Stigma and discrimination was a major barrier to creating and implementing HIV programming.

A study done by King (1989) in one of the outpatient clinics revealed that 20% of the patient with HIV and 43% with full blown AIDS had experienced obvious stigmatizing or discriminating reactions from others because of their infection. Most of the clients we attended to at the MSF-Belgium health facilities experienced the same stigma and discrimination from their close contacts during the first experience of the diagnosis. They even warned health care providers against calling their names with the files in the outpatient department (OPD) waiting bay.

Fear of violence

Women mentioned fear of violence as a Barrier to disclosure in about ¼ of all studies. Some studies specifically probed for fear of violence as a barrier to disclosure, while in others women spontaneously mentioned fear of conflict and violence (Yoshioka *et al* 2001). Fear of violence was mentioned less often as a Barrier to disclosure in developed world studies compared to studies from developing world. Gielen *et al* (1997) found that 12% of the HIV –infected women included in her study in Baltimore, USA, had reported fear of violence as a barrier to disclosure. From developing countries, 16% of the women studied by Kilewo *et al* (2001) in Tanzania, 19% of women studied by Farquhar (2000) in Kenya) and 51% of the women studied by Rakwar *et al* (1999) in Kenya indicated that fear of violence was a major barrier to sharing HIV test results.

Fear of upsetting family members

The 2 studies from the USA that involved Asian/ Pacific Islander Americans, found that fear of upsetting and shaming family was the major barrier to disclosure. Yoshioka *et al* (2001) found that among HIV- infected Men there were 3 major barriers to disclosure of HIV status to family members including; protection of family from shame, protection of family from obligation to help and avoidance of communication about highly personal information. Chin & Kroesen (1999) found that fear of burdening or disappointing others was a major barrier among the Asian/ Pacific Islander women that she studied. In the study from Thailand by Bennetts *et al* (1999) reported that ¼ of the women (77%) felt that HIV was a disease of which their family would be ashamed of.

IV. RESEARCH METHODOLOGY AND DESIGN

In this study qualitative research methods were used to conduct a cross sectional exploration on the barriers to HIV Status disclosure among spouses in Kibera informal settlements in Nairobi county Kenya. The cross-sectional study design was used in obtaining the overall picture as it stood out at the time of the study because according to Babbie (1989), the design is designed to study some phenomenon by taking a cross section of it at the same time in comparison to deferent phenomenon. In this case the two groups of the disclosed and undisclosed clients about their HIV status to their spouses was explored.

This research methods according to Baum, (1998), has been recommended for use in public health research, ‘to study and explain the economic, political, social and cultural factors that influence health and disease in more depth than is possible through a survey’”

A. Location of the Study

The study took place in Kibera informal settlement; with an estimated population of between 600,000 to 1,000,000 at the time of research. The study respondents were residents of Silanga one of the twelve villages and one of the three health facilities; Kibera South Health Centre (KSHC) and Gatwekera HIV clinic that MSF-Belgium ran during the study period before the facilities were handed over to MoH and AMREF in 2016 as an exit strategy having demonstrated to the Government of Kenya that ARVs can work even in the lowest resource setting 15 years down the line.



Figure 1. MSF / MoH Silanga Dispensary offering primary health care with TB/HIV/ AIDS integrated

Source: Field Data (2007)

B. Target Population

The target populations were clients of the MSF-Belgium in Silanga dispensary coming from various villages in Kibera slum, who were HIV-positive and who were attendees of a Post Test Clubs (PTCs) situated in Kibera Slum. The total population comprised of approximately 6 PTCs each with up to 15 members (target population of about 90, most of whom attended the MSF-B clinics). This was out of the twenty PTCs in Kibera with the capacity of 300 memberships. Some members were disclosed while others were not.

The study respondents were people from the target population who had lived in Kibera for at least 12 months, who had been married or had sexual partners for at least 12 months, had tested HIV-positive for the first time more than 6 months prior to the study

C. Determination of the Study Sample & Size

It was not possible to establish a sampling frame for the target population due to the difficulty of identifying and locating members of the target population in the community. Members of PTCs were disclosed or undisclosed about both their HIV status and their membership of a PTC, hence rendering the establishment of a sampling frame difficult. In the absence of a sampling frame, snowball and purposive sampling methods were used to identify study subjects (Baum, F. (1998) & Antelman, G. *et al.* 2001).

Snowball sampling which uses word of mouth and informal and formal networks to identify potential key informants the undisclosed group, in the absence of a clear sampling frame was used.

This involved asking each study subject identified, to recommend or help find other potential study subjects. Purposive sampling aims to identify study subjects with knowledge and experience of the underlying issues of the research topic bowling (1999). This method was used to pick PTC leaders post- test club leaders who had disclosed their HIV statuses and were giving health talks in the health facilities and sharing about the benefits of disclosure. Purposive sampling, both aim to identify and recruit study subjects who are likely to ‘provide rich data and enable a detailed study’ Baum (1998).

The study aimed at recruiting twelve respondents among the target population, 6 of whom had disclosed their HIV-positive status to their spouses and 6 who had not disclosed but were members of PTC which prepares members for disclosure during their sharing sessions. This was purposively sampled and respondents voluntarily offered to participate.

D. Data Collection Instruments

The data collection method chosen for the study was in- depth interviews for focus groups of post -test club leaders who were disclosed about their status to their spouses through focus group and one on one with respondents who had not disclosed their HIV positive status to their spouses. Interviews were conducted via in the counselling room at MSF- Belgium Kibera project.

V. FINDINGS

The study’s objective was to investigate the barriers to HIV positive status disclosure among spouses in Kibera informal settlement in Kenya. Respondents were asked the following question; what barriers did you or are you experiencing in disclosing your HIV status to your spouse. The themes that emerged from the data reflected a wide range of disclosure issues among people living with HIV/ AIDs in Kibera informal settlements.

The following observations and responses were collected from both disclosed and undisclosed participants that reflected the problems encountered:

(Clients 1, 2, 3,4 and 6 represent undisclosed group while FGDs represent disclosed group)

'... He is one person with myths and misconceptions. He does not believe HIV/AIDS exists. He says those with HIV/AIDS are at Mbagathi District Hospital, Kenyatta National Hospital, Koinange street...' [She shakes her head several times and tears start rolling down her cheeks (Su: Client 2)

.... Yes, I tried but he never entertained the story. As usual he would brush me off and pretend he was not listening to me..." [She cries] (Le: Client 3)

'.... I just see separation and no life with me... he will run away completely abandoning me with the children I would rather not disclose to him until he discovers by himself ...'(Su: Client 2)

'... I knew I would stay with the secret. I give them the best when I encourage my children to work hard because anytime I could die. They say, Mum don't say that!!! how can we live without you? This worries me I would be hurt inside but they won't know. Then I say devil go away (gestures at the ceiling with anticipation, shakes her head) they will survive anyway. I have my people who can support the children if I die. My husband is lucky my child is in school. I know in case of anything they will survive. Though I know their father is completely unable. Due to lack of education he might not mind them dropping out of school. I am proud because of this support....' (Ca: Client 6)

'... He will kill me I tell you the truth...[silence she looks down holds her chin] ... Yes this is evident from his response in the house. Because one day we were talking and he said "if I go to hospital with a woman and test positive all of us will find ourselves in graves" I got scared and knew he could kill me...' [Looks contemplative and agitated] '... I told [the counsellor] I can never [disclose to my spouse because he is a very rough Man ... ' [she breaks in tears again longer than before] (Nya: Client 1)

'... My problem is the children ... I don't want my kids to suffer, my mother wanted me to get children to her but he refused. I also don't want to burden them with my children because both my mother and grandmother have high blood pressure ...' (Le: Client 3)

'... Counselling helps a lot but not on disclosure, I have not got enough courage because I have not managed to disclose so far. When counsellors tell you that just go and disclose don't fear that is all, but this is your wife you can sleep with you know, it's not a stranger in the house. This is the most important person in my life it's the mother of my children the woman I have known for my all life. It is not easy as simply the counsellors may put it. I have not got enough counselling support I need support for at least six months or one year then I will disclose....' (Ch: Client 4)

Most of the barriers experience by both groups were similar except the disclosed group mentioned a few that were

different from the undisclosed group which included; fear of partners response, fear of the unknown and denial. Some said:

'...The fear was about what will happen to my marriage if I disclose..... So, the fears were all inclusive including what will happen to my children once they know that I am HIV positive. What will be the perception of the other community members to my children...?. ... Obviously after the disclosure there are bound to be questions about why me, where did it come from,' (FGD C3-JI)

'...I feared that I would be blamed for having contracted the HIV virus thought later on I think I got some courage then disclosed....' (FGD C1-EL)

.....at first it was very difficult on the issue of denial or the aspect of it can't be, it can't be in the family, it's not for me it's for those people it can't be me or my wife...' (FGD C2-RO)

As extracted from statements like those above the most common barriers mentioned by undisclosed key informants included:

- Perceptions of disease,
- Communication barriers,
- Fear of partner and family being discriminated against by community,
- Fear of abandonment/ separation,
- Financial concerns/ repentance,
- Perceived masculinity/gender related barriers,
- Fear of violence,
- Weak social support structure for disclosure,
- Fear of isolation, shame, rejection stigma,
- Not knowing how to disclose.

Disclosure not addressed adequately by counsellors.

VI. DISCUSSION AND SUMMARY

Stigma & Discrimination

Stigma and discrimination were found to be key constraining factor to all respondents. Most treatment program including MSF-Belgium try to reduce stigma by encouraging disclosure to at least one member of the family such as treatment support but they still find it hard.

Respondents from FGD said that while it's not easy to disclose their HIV status to community members they do not know well, it is very easy to do so among other PLWHAs. They generated many comments about stigma discover and disclosure (see results)

Stigma and discrimination apparently cut across all the interactions in life. Bowling (1999) narrates about a Haitian woman who was advised by medical personnel to procure an abortion because she was positive. Her decision to continue the pregnancy was over-ruled and an abortion was performed without agreement and even counseling.

The researcher felt strongly that stigma undermines one's identity and capacity to cope with the disease hence hinders disclosure. Skinner and Mfecane (2004) argue that the same fear acts as stumbling block to disclosure to spouses and to potential important sources of support. However, Jackson (2002) urges that it is HIV positive people who will fight and win their battle against stigma and discrimination.

According to testimonies of respondents, stigma remains a major problem. Moreover, disclosure and stigma seem to be different sides of the same coin.

On one hand, it was reported that disclosure may cost the individual their jobs, family and social support. On the other hand, a substantial number of respondents especially those who had disclosed were receiving support from family members.

Although disclosure can have both negative and positive effects it was more generally linked to better and more positive living and support.

Gender / violence issues

Gender inequality and violence are critical factors in spreading HIV/AIDS. Skinner (2004) argues that gender constraints exacerbated by HIV/AIDS include gendered violence, uneven and inequitable wealth distribution and biases by those in authority who have power to allocate resources. In view of these sentiments, all female respondents who had not disclosed mentioned fear of violence.

Studies from development countries as indicated in the literature review, by Kilewo (2001), Tanzania, Farquhar (2000) and Rakwa (1999), Kenya, indicated that fear of violence was a major barrier to sharing HIV positive status results to significant others. The researcher concurs with Mbaya (2002) when He quips that in East African customary patriarchal systems with males heading the households fuel the inequality.

Respondents mentioned that violence manifested through sexual abuse, assaults, abandonment, rejection on disclosure and even physical assault. In the context of gender equality male attitudes and behaviors appear to be the center of HIV/AIDS problems (UNAIDS 2001).

Poverty and financial dependency

Out of the 12 respondents interviewed, there was a strong linkage between poverty, illiteracy and barriers to HIV positive status disclosure. Due to fear of being abandoned together with the children by their spouses, most respondents resorted or vowed never to disclose their status to the spouses as expressed in the findings:

This exposed them more to re- infection and non-adherences to medication as there was a linkage between non-disclosure and non-adherence to medication. Kaleeba (2001) reckons that feminizations of poverty are enhanced by women's

disadvantages in terms of access to resources, liabilities, and lack of upwards mobility among others.

Inadequate knowledge on disclosure

Most of respondents especially those who had not disclosed said there was inadequate knowledge on disclosure and they feel that this had not been addressed adequately by counsellors. Counselling is a key requirement for successful disclosure process and eventually to adherence to ARTS. However, it was indicated that there was intensive counselling during testing after which there was very little counselling unless they had particular challenges. Yet it is well recognized by Horne that disclosure and adherence rate decline with time (Horne *et al* 2001).

If a patient has not disclosed then, the counsellor would suggest approaches to disclosing. But again, to whose benefit is disclosure? From the findings it's true that there is more risk in disclosing the status to partners than not disclosing at all. One female respondent reported to have been abandoned, rejected or physically assaulted on disclosing.

It was also evident that counsellors needed to be equipped more in disclosure issues.

Lack of knowledge and counter-productive beliefs.

To have successful disclosure of HIV positive status program depends on certain level of knowledge and awareness among PLWHAs and ARV users. However, this study found a wide variation in the level of knowledge among respondents about HIV/AIDS and disclosure.

While knowledge about HIV/AIDS is generally good, believes and misconceptions that people have been bewitched, had a spell cast, or been afflicted by an AIDS devil, or HIV/ AIDS belongs to prostitutes as indicated in findings are common place and inhibit disclosure among spouses. Most respondents expressed that myths and misconceptions and communication barrier from the spouse as a hindrance to disclosure. Greater efforts are needed to educate both the community and PLWHAs about HIV in an effort to dispel beliefs about witchcraft and misconceptions.

VII. CONCLUSION AND RECOMMENDATIONS

In conclusion, stigma, discrimination disempowerment, poverty and, for women, gender inequality cripples and affect the infected people's coping mechanisms

It's therefore recommended that;

On-going counselling and HIV support groups through post - test clubs (PTCs), may present a key opportunity for discussing fears and concerns around disclosure as well as sharing disclosure strategies amongst peers.

Community- based programs are needed to reduce stigma associated with HIV/AIDS.

Social support for example through support groups or ongoing counselling may help HIV-infected individuals to overcome the barriers to disclosure.

Promotion of couple counselling is an important step to facilitate positive outcomes and minimize negative outcomes

REFERENCES

- [1] Antelman, G. et al. (2001) Predictors of HIV-1 status disclosure: A prospective study among HIV-infected pregnant women in Dar es Salaam, Tanzania. *Aids*, 15:1865-
- [2] Babbie, E. (1989) *The practice of Social research*. California, Wadsworth Publishing Company 1874.
- [3] Baum, F. (1998) *The New Public Health: an Australian perspective*. (1st edition). Melbourne: Oxford University Press.
- [4] Bennetts, A. et al. (1999) *Determinants of depression and HIV-related worry among HIV-positive women who have recently given birth, Bangkok, Thailand*. *Social Science and Medicine*, 49:737-749.
- [5] Bowling, A. (1999) *Research Methods in Health*. (3rd Edition). Buckingham, Philadelphia: Open University Press.
- [6] Chin, D. and Kroesen, K. W. (1999) *Disclosure of HIV infection among Asian/Pacific Islander American women: Cultural stigma and support*. *Cultural Diversity and Ethnic Minority Psychology*, 5:222-235.
- [7] De Rosa, C., and Marks, G. (1998) *Preventive counselling of HIV-positive men and self-disclosure of status to sex partners: new opportunities for prevention*. *Health Psychology*, 17: 224-31.
- [8] Farquhar, C. et al. (2000) *Prevalence and correlates of partner notification regarding HIV-1 in an antenatal setting in Nairobi, Kenya*. In: International Conference on AIDS; 381.
- [9] Gielen AC, O'Campo P, Faden RR, & Eke, A. (1997) *Women's disclosure of HIV status: experiences of mistreatment and violence in an urban setting*. *Women's Health*; 25:19-31.
- [10] Kaleeba, N., Kadowe, J.N., Kalinaki D., Williams, G. (2001) *Open Secrete. People facing up to HIV and AIDS in Uganda*. Strategies for Hope Series No. 15, London: Action Aid.
- [11] Kilewo, C. et al. (2001) *HIV counselling and testing of pregnant women in Sub-Saharan Africa*. *Journal of Acquired Immune Deficiency Syndromes*, 28:458-462.
- [12] Mbaya, S. (2002) *HIV/AIDS and its Impact on Land issues in Malawi*. Paper presented to the FAO/SAPPN Workshop on HIV/AIDS and Land, Pretoria 24-25 June.
- [13] Rakwar, J. et al. (1999) *HIV/STD: the women to blame? Knowledge and attitudes among STD clinic attendees in the second decade of HIV/AIDS*. *International Journal of STD & AIDS*, 10:543-7.
- [14] Simoni, J. et al. (2001) *HIV disclosure among women of African descent: associations with coping, social support, and psychological adaptation*. *AIDS and Behaviour*, 4:147-158.
- [15] Skinner, D. and Mfecane, S. (2004) *Stigma, Discrimination and the Implications for People living with HIV/AIDS in South Africa*. *Journal of Social Aspects of HIV/AIDS*. Vol.1 No.3
- [16] Stynes, R., Lipp, J., and Minichiello, V. (2009) *HIV and AIDS and "family counselling": A systems and developmental perspective*. *Counselling Psychology*, Vol9, No 2 pp131-141.
- [17] UNAIDS (2015) *Report on the Global AIDS Epidemic*. 4th Global Report. Geneva
- [18] UNAIDS (2011) *Population Mobility and AIDS, Technical Update*, Geneva: UNAIDS.
- [19] UNAIDS (2004) *Report on the Global AIDS Epidemic*. 4th Global Report. Geneva
- [20] WHO (2011) *Opening up the HIV/AIDS Epidemic: Guidance on encouraging beneficial disclosure, ethical partner counselling & appropriate use of HIV case reporting*. Geneva, UNAIDS/00.42E.
- [21] Yoshioka, M.R. Schustack A., (2001) *Disclosure of HIV status: Cultural issues of Asian patients*. *AIDS Patient Care and STD's*; 15:77-82.
- [22] Maman, S. et al. (2013) *Rates and correlates of HIV status disclosure to sexual partners among women at a HIV VCT clinic in Dar es Salaam, Tanzania*. (Unpublished).