Factors Influencing Disclosure of HIV-positive Status among People Living with HIV in Kirinyaga County, Kenya

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ABSTRACT

The paper reports results from a study that investigated factors influencing the disclosure of HIV-positive status to one's spouse in Kirinyaga County in Kenya. HIV status disclosure is critical to HIV prevention and access to health care and treatment. Thus disclosing ones HIV-positive status to one's spouse is crucial in HIV prevention. Failure to disclose one's HIV-positive status compromises risk reduction and exposes one's spouse or other sexual partners to infection if they are not already infected. The research adopted a qualitative approach. The sample consisted of People Living with HIV/AIDS (PLWHIV) attending selected Comprehensive Care Centres (CCC) in the County. Data was collected from a convenience sample of 98 PLWHIV using semi-structured In-Depth Interviews. The data was analysed thematically. The study found that the decision to disclose or conceal one's HIV-positive status to a spouse is influenced by several factors including the stage of illness, fear and privacy. The study also found that perceived spousal communication behaviours influenced the decision to disclose or conceal a HIV-positive status. The study concludes that disclosure is influenced by a myriad of factors that either result in the PLWHIV disclosing or concealing their HIV positive status. The study recommends that couples should be encouraged to test together thus easing the process of disclosure.

Key words: Self- disclosure, People Living with HIV, Spouse, Factors influencing disclosure

1. INTRODUCTION

HIV/AIDS continues to exact an enormous toll on social and economic development in several countries in the world. UNAIDS (2017) indicates that in 2016 there were 36.7 million People living with HIV (PLWHIV) globally. According to NACC and NASCOP (2012, p. 4) by December, 2011, there were 1.6 million PLWHIV in Kenya (KAIS, 2012). The HIV prevalence rate in Kenya is at 5.6% and 4.0% in Kirinyaga County (KAIS, ibid.). In Kenya, sexual transmission accounts for 93% of new HIV infections with heterosexual sex representing 77% of the infections (NACC and NASCOP, ibid. p.2). Like other areas in the country, HIV/AIDS in Kirinyaga has far-reaching socioeconomic effects having a total of 12,654 PLWHIV by end of 2013 (Kirinyaga County HIV and AIDS Strategic Plan 2014/2015-2018/2019).

Self-disclosure is defined as "the process of making intentional revelations about oneself that others would be unlikely to know and that generally constitute private, sensitive or confidential information" (Pearson, Nelson, Titsworth & Harter, 2003, p.187).

Spouses have not "traditionally" been seen as a "risk population" since what has been viewed as "high risk" is sex outside the marital union (KAIS 2007, p.18). Zulu and Chepngeno (2003) observe that most preventive strategies emphasize abstaining from sex or using condoms. They argue that these are appropriate strategies for individuals to avoid infection outside marriage but are not perceived by couples to be appropriate within marriage.

Individuals infected with HIV are faced with a decision of whether to conceal or disclose their HIV status to their spouses. Self-disclosure is a difficult task that creates both vulnerabilities and opportunities. Disclosing private information makes one vulnerable since information about one's HIV-positive status is highly risky. Self-disclosure however creates opportunities to access health care, social and psychological support for the PLWHIV and their families. Disclosure would enable individuals to make informed choices to prevent further infections.

Despite these benefits of HIV disclosure, not all PLWHIV disclose their HIV-positive status to their sexual partners. KAIS (2012) indicates that 65.4% of HIV infected Kenyans who had one or more sexual partners in the last twelve months had disclosed their HIV status to their partners. This leaves 34.6% who have not disclosed their HIV-positive status. It also indicates that among married or cohabiting partners, 4.8% were HIV sero-discordant where one partner is infected and thus posing a risk to the uninfected partner. KAIS (ibid. p.8) notes that heterosexual sex within a union or regular partner accounts for 44.1% of new infections yet these groups are rarely the target of HIV prevention programs. There is thus a need to address the spousal unit as an intervention for HIV prevention due to the potential risk of infection if the infected individual does not disclose their HIV-positive status to the spouse. Since there is no cure for HIV, self-disclosure can be an important tool for HIV prevention, care and support. The study investigated factors that facilitate or hinder disclosure of a HIV-positive status to one's spouse.

2. METHODS

The study employed qualitative methods of research. The primary population selected for this study were PLWHIV from three purposively selected health facilities in Kirinyaga County. These were Kirinyaga District Hospital; Mwea Mission Hospital and Sagana Health Centre which have comprehensive care centres (CCC). A convenience sample of 98 PLWHIV consisting of 34 males

and 64 females were interviewed using semi-structured in-depth interview schedules (IDI). Seven key informants were also interviewed. The data was then analysed using thematic analysis.

2.1 Ethical Issues

The respondents were briefed on the purpose and objectives of the study and those who consented to participate were interviewed. They were assured of confidentiality and anonymity as their names are not used in the study. We used codes to refer to the PLWHIV. After each interview, the respondents were given an opportunity to ask any question or raise any issues of concern which we did our best to respond to or refer them to persons and facilities for further help.

3. FACTORS INFLUENCING HIV-POSITIVE STATUS DISCLOSURE

The study explored factors that motivate PLWHIV to disclose and those that prevent them from disclosing their HIV-positive status to their spouses.

3.1 Motivating Factors for HIV-positive Status Disclosure

The PLWHIV who had disclosed cited various reasons for disclosing their HIV-positive status to their spouses. The major themes that emerged were being sickly, fear, wanting the spouse to test, spousal communication and relationship factors, privacy and psychological factors.

First, the main reason cited by most PLWHIV was that they were sickly and had been in and out of hospital several times. One PLWHIV said that he was so sick that even if he had not disclosed his HIV-positive status, the spouse would still have known his status. He explained "I was so sick that even if I had not told her, she would have known since she is the one who was taking care of me. Again she had suspected it when I got T.B" (disclosed male). For others, their spouse was sickly and thus the PLWHIV chose to disclose their status to save the spouse from being infected in case they were not already infected. One respondent explains, "Surely I could not wait to see my husband in a similar state; I had lost weight because of T.B., so I believed the earlier the better as I was trying to save him" (disclosed female).

The second theme that emerged was fear. Respondents expressed fear of different things. Some expressed fear of infecting their spouses and thus opted to disclose their HIV-positive status, others feared that their spouses would find out their HIV- positive status after keeping it secret and fear of the spouse finding the Antiretroviral (ARVs) and demanding an explanation. A PLWHIV expressed her fears, "I feared what the daktari [doctor] had cautioned me about infecting him, just in case he was not positive and also I feared that my husband might turn hostile if he realized that I was positive but opted to keep it a secret" (disclosed female). Some were afraid to introduce condoms which health care providers had advised them to use to protect their spouses or sexual partners. One PLWHIV commented, "I was advised by the doctor to bring her for the test and that we should use condoms. I was afraid because I did not know how to introduce condoms in our marriage, so I disclosed to her to ease the way for safer sex and to avoid resistance" (disclosed male).

The third theme was perceived spousal communication behaviours and relationships. PLWHIV either perceived their spouses' communication behaviour as supportive which was described as being "good" or defensive which was described as "bad". Some PLWHIV reported disclosing their HIV-positive status to their spouses because they perceived them as having certain supportive

characteristics. These included having trust and confidence in their spouses to keep the information confidential or provide support. This could be financial or emotional support. In response to the question on why they disclosed a PLWHIV said, "Further he was the one supporting me at that time of illness. I have no other hope in life apart from him" (disclosed female).

Fourth, some PLWHIV attributed the disclosure of their HIV-positive status to their spouses to anger. This was expressed by some female respondents who expressed anger that their spouses had been unfaithful and had infected them. Others were angry because their spouses knew of their HIV-positive status and had been on medication without informing them. One PLWHIV expressed her anger: "I had pain because he knew of his condition but he kept it a secret, he then went ahead and married another woman and they are both taking ARVs. So he had left me to die" (disclosed female). Some PLWHIV expressed helplessness as one respondent said, "I told him because even if I hid it from him, I would not have changed it, there was no need of hiding because I could not change anything as I was already HIV-positive" (disclosed female). The reasons given for disclosing HIV- positive status to their spouses are summarized in table 1.

Table 1: Reasons for Disclosure to one's Spouse

	Disclosure to one's Spouse
Category	Specific reasons
Illness	1. Frequent illness for PLWHIV, spouse or both.
HIV Testing Related	1.To get the spouse to agree to be tested
	2. To plan to start a family or to get pregnant
	3. To help the spouse take action early
	4. Spouse had insisted on HIV test
	5. They tested together
Spousal Communication/ Relationship Factors	6. Following health care provider's advice
	1.PLWHIV cares and loves the spouse
	2. Spouse is supportive
	3.To be open
	4. To encourage the spouse
5 1 1 1 1/5 1	5.To console and comfort the spouse who is also HIV positive
Psychological/Emotional	6. PLWHIV saw the need for the spouse to know the truth
	7.PLWHIV thought the spouse is also infected
	8. To discourage the spouse from having sex with PLWHIV
	9. PLWHIV knew that the spouse would eventually know 10. To see the spouse's reaction
	11. The spouse also disclosed to the PLWHIV
	11. The spouse also disclosed to the LLWIIIV
	1.To ease the burden on oneself or on the spouse
Privacy	2. Confusion, how to take or hide ARV without the spouse's knowledge
	3.To help the spouse accept themselves
	4. Guilt
Fear	5. Realizing that they are in this together.
	6.Pain
	7.Anger
_	8.Stress
Protection	9.Denial
	10. Loss of control
Overtions	11.Inability to change the situation of being HIV positive
Questions	1,Spouse can keep their secret
	2. Spouse cannot spread rumours about The PLWHIV's status
	3.PLWHIV can trust spouse with the secret
	3.12 WITH Can dust spouse with the secret

- 1.Fear of infecting the spouse
- 2.Fear that the PLWHIV would die
- 3. Taking ARVs without the spouse finding out
- 4. Spouse asking for sex
- 1. Save the spouse from a similar situation
- 2. Protect the spouse; avoid infecting the spouse in case they are HIV-
- 1.To respond to questions from the spouse
- 2.To avoid questions from the spouse
- 2. The spouse demanded to know what the doctor had said
- 3. To confirm rumours about the PLWHIV's HIV status

3.2 Motivating Factors for Non-Disclosure

The study looked at what prevents PLWHIV from disclosing their HIV-positive status to their spouses. Two main themes emerged: fear; communication and spousal factors. Other themes were privacy and communication skills.

The first theme for concealing HIV positive status from their spouses was fear. An overwhelming majority of the PLWHIV interviewed expressed fear of one consequence or another. Fear cut across the non-disclosed respondents with most respondents expressing more than one kind of fear. They expressed fear of being stigmatised, blamed for bringing the virus home or perceived as immoral. They reported fearing a spouse's reaction; the spouse may revenge for instance by being unfaithful; separation; violence; spouse leaving; shame; abandonment; gossip, rumours and fear of information about one's HIV-positive status reaching their in-laws. Most PLWHIV who have not disclosed their HIV-positive status said that at least "no one knows" and they can "live like normal people"

A male PLWHIV explained, "I fear she might leave me, she might know I am the one who brought the disease and decide to take revenge, she might even take the news to my in-laws, I fear that" (disclosed male). A respondent who had disclosed to her first spouse was rejected and abandoned and she feared disclosing to the current spouse may elicit similar consequences. She narrated her fears as follows, "I fear that I might be faced with the problems that befell me once I disclosed to the first husband. I feared shame, abandonment, denial, blame. The man hated me and even married again. I fear if I disclose, I may carry the same burden" (non-disclosed female). One Key Informant said, "Most PLWHIV do not disclose to their spouses, they have fear of the unknown. Ladies fear they will be left by their husbands and as for the men they fear that they will be blamed for being unfaithful that is why they got infected" (clinical officer).

The second theme was communication and spousal factors. PLWHIV reported not disclosing to their spouses due to spousal characteristics and their perceived communication and relationship with their spouses. Some PLWHIV reported that their spouses were not supportive either emotionally or financially and hence they did not see the need to disclose to them. Others were perceived as judgemental and not concerned about the PLWHIV. One woman remarked, "My husband is just there, most of the time he does not care what we eat or drink, he's just there... so I do not think it is necessary to disclose to him" (non-disclosed female).

Some PLWHIV reported not disclosing to their spouses to avoid risking the status of their relationship as one PLWHIV narrated, "I have been desperate for love, so by getting him it was a golden opportunity of which I think I should keep my HIV status as a secret to secure my

relationship, although I work towards any step that would make him know that I am HIV- positive like requesting him to have a HIV test and discussing about HIV/AIDS" (non-disclosed female). The reasons given for not disclosing their HIV-positive status are summarized in table 2.

Table 2: Reasons for Non-Disclosure to Spouse

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4. DISCUSSION

From the study, participants cited various reasons for disclosure and non-disclosure of their HIV-positive status to their spouses. Petronio (2002) notes that, factors such as culture, gender, motivation, context and risk-benefit ratio can influence one's decision to reveal or conceal private information. Derlega and Grizalek (1979, as cited in Petronio et al. 1993, p.225), cite five reasons for disclosure: expression, some clarification, social validation, relationship development and social control. Thus the decision to either disclose one's HIV-positive status or withhold the information will be informed by several factors.

The study found that majority of PLWHIV who disclosed their HIV-positive status reported being very sickly. The stage of their illness was a motivator in disclosure of their HIV-positive status

either to access health care and support benefits or for others to get their spouses to get tested. Disclosing was a way of protecting the spouse from infection for those who may not have been infected. This finding seems to be in line with Petronio's (2002) argument that some life events will result in changes or modification of privacy management. When a PLWHIV becomes too sick, often one loses control over one's previously tightly held privacy boundaries over their HIV-positive status information and open it up to allow access to one's spouse. This also seems to be in concurrence with the theory of disease progression which states that, individuals disclose their HIV diagnosis as they become symptomatic and have to explain frequent hospitalization and drug use (Kalichman 1998, as cited in, Serovich 2008).

Fear was a main factor in influencing disclosure of HIV-positive status. It could result in a PLWHIV loosening control of their boundary surrounding the HIV-positive status information and allow access to the spouse. However, it could lead to a tighter control of the boundaries and the PLWHIV being more closed up and the HIV-positive information is withheld from the spouse. Although most literature looks at fear as a barrier to disclosure, fear can also motivate revealing one's HIV-positive status. The majority of PLWHIV who had not disclosed their HIV-positive status to their spouse reported fear as a key deterrent. Studies have found similar results that fear is a major barrier in disclosure of HIV-positive status to partners. Wolfe et al.(2006) found that 69% of patients did not disclose their HIV- positive status to their family and a majority of those who reported delaying testing for HIV did so due to fear of HIV/AIDS stigma. According to Lane and Wegner (1995, as cited in, Petronio, 2002, p.68), "people keep secret information because there is the fear of real or imagined repercussions that the information would bring with exposure"

Fear of stigma was cited by both the disclosed PLWHIV and non-disclosed PLWHIV. Since HIV is mainly transmitted through heterosexual sex in Kenya, it is thus associated with taboo subjects in most Kenyan communities. UNAIDS (2005) argues that stigmatisation poses a barrier to the prevention, care and treatment of HIV/AIDS. UNAIDS (ibid.) notes that the fear of stigma and discrimination discourages many PLWHIV from disclosing their HIV infection to their spouses and even family members who could be a necessary support system. Petronio (2002) says that most individuals must consider the stigma risks before concealing or revealing their private information. Rohleder and Gibson (2005) note that the fear of stigmatisation is due to potential negative consequences for being identified and labelled as HIV positive either accessing treatment or support.

From the study some respondents expressed their concerns about HIV/AIDS and the question of moral values. Most talked of being perceived as a "sinner" or "a prostitute" or members of the community refusing to buy from their shops. As a consequence of these fears, PLWHIV keep their diagnosis secret, tightly protecting the information. They protect themselves from the consequences of disclosure by withholding information about their HIV-positive status. Greene et al. (2003) argue that fear of stigma contributes to PLWHIV setting up defensive boundaries around their private information. Many PLWHIV will go to great lengths to avoid being seen by people who might know them at the Comprehensive Care centre (CCC) including missing an appointment or registering at a heath facility many kilometres away to minimize the risk of their HIV status being known as HIV-positive.

From the study very few PLWHIV attended Couple Voluntary Counselling and Testing (CVCT). Majority of them tested alone usually at the request of the health provider using Provider Initiated HIV Testing and Counselling (PITC). While CVCT would ease disclosure, it was not the most commonly used approach to HIV testing. Iwan (2007) in their study in Kilifi, Kenya observed a low uptake of CVCT.

PLWHIV appraise their situation and the positive and negative possible consequences of disclosure before making the decision to either disclose or withhold information about their HIV-positive status. The higher the risk anticipated by revealing the private information the lower the probability of disclosure and the reverse would hold. The study results indicate that most PLWHIV had anticipated negative outcomes. Studies have shown that perceived negative reactions discourage people from being open about their HIV status (Kalichman et al. 2001; Greene et al. 2003).

In the study, fear of violence especially for some women also prevented disclosure. Some women reported not disclosing and not using condoms for fear of making their husbands angry or fear of their reactions. This reflects vulnerability among most women. Gillet & Parr (2010) in their study in Kenya found that many women in rural Kenya chose not to disclose their HIV-positive status for fear of negative outcomes such as blame and rejection.

This study suggests that economic considerations can influence a PLWHIV's disclosure decisions not only to their spouses but also to family members. Majority of PLWHIV reported facing financial difficulties as most engage in small scale farming, small scale businesses and casual labour. Some respondents especially women reported disclosing to their spouses in order to get financial support and to avoid many questions every time they ask for money to attend clinic. No male reported disclosing due to the need for financial assistance from their spouses. These reflect the gender inequality and economic dependence of women on their male partners resulting in higher vulnerability to HIV. International Council of AIDS Service Organization (ICASO, 2007, p.18) notes that economic factors are intrinsic to the HIV epidemic and can stimulate risky behaviours that are responsible for HIV transmission, create obstacles to prevention and impede efforts to cope with the epidemic.

Two key pre-requisites were identified as important in the disclosure decision. These were trust and support. HIV-positive status is highly private information and individuals go to great lengths to protect it. Palmer and McMahon (1997) note that people go to great lengths to protect themselves and their families from what they perceive as dangerous knowledge. Human beings go to great efforts to keep or withhold information, which they believe if known would cause more harm. This follows the script of "what you do not know does not hurt". Bradshaw (1995, p.43) concurs that protection is a common motivator for keeping secrets.

From the study PLWHIV were willing to open their private boundaries if there was trust and support from the spouse. Rothwell (2000, p.46) says that, "when one person trusts another to keep the information confidential and not to reveal it to others then disclosure is likely to occur"

5. CONCLUSION

The study investigated factors influencing disclosure and non-disclosure of HIV-positive status to spouses among PLWHIV in Kirinyaga County in Kenya. The study findings show that all the PLWHIV including those who had not disclosed were aware that they needed to disclose their HIV-positive status to their spouses as they had been advised by the healthcare providers. The results indicate that disclosure is mentally, emotionally and socially difficult hence creating a gap between the knowledge and disclosure. Although disclosure has benefits that the PLWHIV are aware of, it also entails taking a risk and making the PLWHIV vulnerable. The study established that disclosure is dependent on different interdependent factors which influence the PLWHIV to either disclose or conceal their HIV-positive status.

The study concludes that spousal communication behaviours and perceived relationship are important in disclosure. Another conclusion is that disclosure can facilitate HIV prevention since PLWHIV who had disclosed their HIV-positive status to their spouses found it easier to discuss

HIV prevention measures and safer sex with their spouses unlike those who had not disclosed. Also those PLWHIV who had not disclosed their HIV positive status had difficulties adhering to the antiretroviral therapy (ART). This was mainly because they had not disclosed to their spouses and thus had difficulties in observing the schedule recommended by the healthcare provider and also challenges in negotiating for safer sex. This calls for measures to help increase adherence among the PLWHIV especially in low income populations and rural communities.

The study recommends assisted disclosure should be offered as an available option for all HIV positive individuals since by the time a PLWHIV decides to disclose, they may have already exposed the spouse and other sexual partners to HIV infection. From the study very few participants had attended couple counselling as most had tested alone and hence the study recommends the need to increase and facilitate couple counselling and testing which would ease disclosure. There is need for further research to address the barriers and challenges that prevent couples from going for CVCT.

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