My Biggest Secret: Private Information among People Living with HIV and their Spouses in Kirinyaga County, Kenya

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ABSTRACT

This paper reports results on what People Living with HIV (PLWHIV) in Kirinyaga County, Kenya consider as private information. It is part of a larger study on factors influencing disclosure of HIV-positive status among PLWHIV in Kirinyaga County. Individuals make a choice whether to tell or not to tell what they consider to be their private information. While certain information is easily shared between the PLWHIV and their spouses, there is information that is considered private and concealed from their spouses. Most PLWHIV considered their HIV-positive status as private information and often referred to it as "my biggest secret". PLWHIV went to great lengths to control who gained access to information about their HIV-positive status. This included cautioning a spouse not to reveal the HIV-positive status to anyone else for those who had disclosed and lying to protect their private information for those who had not disclosed. Other topics considered private include the "source of HIV infection", *mpango wa kando* (concurrent sexual partners), their Personal Identification Number (PIN) for bank and *Mpesa* (Mobile phone based money transfer) accounts.

Key words: Private Information, Biggest secret, People Living with HIV, Spouse, Self-disclosure

1. INTRODUCTION

Individuals make judgements about the degree of privacy and openness that they wish to maintain in a given interaction (Petronio, 2002, p.15). Some exercise high levels of control over their information and conceal the information, while others exercise low control and allow information to pass to either one other person or more than one. Stewart and Logan (1993, p.50) suggest that there are five needs that influence our personality and relationship growth. One of them is the need for privacy which is in opposition to the need for disclosure. Gamble and Gamble (2002, p.237) observe that we often have tensions between disclosure and concealment. They note that for most people, complete openness is intolerable. On one hand individuals want to share their inner selves with people they care about deeply and on the other hand there are times when they do not feel like sharing and wish to maintain privacy. Individuals need to balance their needs for openness and privacy.

UNAIDS (2017) indicates that in 2016 there were 36.7 million people living with HIV (PLWHIV) globally with 1.8 million people newly infected with HIV in the same year. 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).

Private information refers "to the content of what is disclosed" (Petronio, 2002, p.5). Each individual has information that they consider private. Self-disclosure is "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 and Harter (2003, p.187). Most PLWHIV regarded their HIV-positive status as their private information because disclosing it makes them vulnerable. Privacy is the feeling that one has the right to own private information either personally or collectively (Petronio, 2002, p.6). Schoeman (1984, as cited in Petronio, 2002, p.9) says that privacy is regarded as "a claim, entitlement or right of an individual to determine what information about himself or herself may be communicated to others"

Petronio (2002, p.3) uses the metaphor of "boundary" to demarcate between what is public and what is private. Individuals erect boundaries around their private information and they can decide to either keep the information private within the personal private boundary where information is only known to the self, or let others in and reveal the private information. Berko et al. (1992, p.210) note that, "We each have a public "I" and a private "I, in communicating with others, we are constantly evaluating what we decide to share and what we choose not to share". Individuals may reveal private information for various reasons. They may include, "intimacy to relieve a burden, gain control, enjoy self-expression or develop intimacy" (Petronio, ibid. p.6).

According to Greene et al. (2003, p.13), people believe that their private information belongs to them and they want to control the flow of that information because they believe that they own it and disclosure makes them vulnerable. Individuals believe that they own their private information and should have control over who may or may not have access to it. Hence, they can control whether anyone else gets access to the information, how and when? Individuals want control over their private information because there are risks involved when this information is managed by others. Petronio (2002) identifies security risks, stigma risks, face risks, relational risks, and role risks. This paper discusses what PLWHIV in Kirinyaga County considered as private or not private information.

2. INFORMATION NOT CONSIDERED PRIVATE BY PLWHIV

The PLWHIV pointed out a number of topics that they generally share with their spouses which is not considered private information.

2.1 Information not Considered Private by all PLWHIV

Most felt that there are things that one generally shares with their spouse by virtue of being married. This was echoed by the use of phrases such as, "general issues, family welfare and general talk". A PLWHIV said, *"We discuss life in general and since we are married we talk about everything"*.

2.1.1 Family Welfare

Most PLWHIV both disclosed and non-disclosed acknowledged discussing with their spouses issues to do with their family's welfare. The main topics generally discussed included children and family welfare; farming; *kibarua* (casual work) and business. Business here largely refers to small scale trading commonly referred to as *jua kali* (informal business sector) in Kenya as most of them operate in the open hot sun or in temporally shelters.

One respondent said, *"We discuss about development of our home, bringing up children, like we have a son who is supposed to go to college, so we discuss how to help him"* (disclosed female). They also cited discussing family development such as building a bigger house, buying a plot, buying bulls for ploughing, house rent and whether one is going for *kibarua (*casual work). Farming issues are generally shared between spouses as most of the PLWHIV are small scale farmers. These include issues to do with land preparation, planting, harvesting, livestock and planting tomatoes in plastic bags for home consumption.

2.2 Information not Considered Private by PLWHIV who had Disclosed their HIV Status

Among PLWHIV who had disclosed, they discussed with their spouses issues on HIV, death and reciprocity where a spouse felt the need to share their HIV status because the PLWHIV had already disclosed theirs.

2.2.1 HIV-positive Status

The topic of HIV status was not considered private information by PLWHIV who had disclosed their HIV-positive status to their spouses. They reported discussing issues such as positive living, eating a healthy diet, taking antiretroviral drugs (ARVs) and drug adherence, HIV prevention and how to protect the uninfected spouse from infection and the need for the spouse to go for HIV testing. One respondent narrated how the spouse encourages him to continue with life. He explained, *"She encourages me and assures me that I will live as long as God wants because for me being infected is like an accident"* (disclosed male).

Most respondents especially in cases where both spouses are HIV-positive talked of reminding each other to take their ARVs, the need for eating a healthy diet, preventive measures such as the use of condoms and cautioning each other about infidelity. One PLWHIV explains, *"We usually talk about the need to be faithful to each other to avoid infection from other people, our future and children's wellbeing"* (disclosed male). Among some discordant couples, the topic of HIV testing was discussed with the HIV-positive partner encouraging the spouse to go and get tested. A respondent explains their discussion, *"We usually talk about him being tested frequently to know for real if he is HIV positive or negative. We usually do not talk much because he is in denial"* (disclosed female). For those PLWHIV who are still in their childbearing age and would like to have children, issues of Family Panning (FP) and fear of infecting the child due to their HIV- positive status were discussed.

2.2.2 Death

The topic of death was discussed among some of the PLWHIV who had disclosed their HIV-positive status to their spouses. Some of the issues that were discussed pertaining to death included the wellbeing and future of their children after the death of parents especially where both parents are HIV-positive, issues of inheritance, properties owned and the reality of death. A PLWHIV explained that they discuss death with the spouse so that they can plan for their children in the event that both of them pass on. She asks, *"If by any chance we were to die, how would we leave our children?"* (disclosed female). A PLWHIV described how he informs his wife about his properties just in case he dies. He reported, *"We usually talk about how we can develop our home. I also tell my wife about my properties so that she can know what to do in case of my death"* (disclosed male).

2.2.3 Reciprocity

The theme of reciprocity was brought out by some PLWHIV who felt that they shared with their spouses everything including the HIV-positive status because the spouses also shared with them. This was the sentiment of one respondent who said, *"There is nothing I cannot share with my husband because there is nothing to hide. He even knows my HIV-positive status as well and I also know his"* (disclosed female). These PLWHIV were of the opinion that once they had disclosed their HIV-positive status to their spouses, there was nothing else that they could not share. However, some respondents felt that although they shared everything with their spouse, they were not very sure if the spouse was also sharing everything with them. This sense of doubt and uncertainty was expressed by some respondents especially the females in response to what kind of information they consider private and may not share with their spouse. One said, *"Nothing, I do trust him although I do not think that this feeling is mutual, because he does not trust me"* (disclosed female).

3. PRIVATE INFORMATION

This is information that the PLWHIV considered to be private information and withheld it from their spouse. These are one's HIV-positive status, finances, PIN numbers and sexual issues.

3.1 HIV-positive status

Most of the PLWHIV both the disclosed and non-disclosed considered their HIV-positive status to be private information. Understandably, for the non-disclosed PLWHIV, this is information that they would go to great lengths to keep private and conceal it as they would not want anyone including their spouses to know. This was mainly attributed to the fact that they have not disclosed their HIV-positive status and this is a topic that they would rather avoid and withhold the information. A respondent explained, *"We talk about business, school fees, we talk about those things, since I got infected I do not like discussing about HIV, there was a time she had asked me to get tested but I refused"* (non- disclosed male).

For the non-disclosed PLWHIV, their HIV-positive status was private and highly protected to keep the spouse from knowing. When the topic of HIV was discussed it was to caution the spouse or discuss the risks of HIV/AIDS as one PLWHIV explained, *We discuss love affairs and issues to do*

with multiple partners and mpango wa kando (concurrent sexual partners) *and the risks involved"* (non-disclosed female).

Even among those PLWHIV who had disclosed their HIV-positive status to their spouses, it was still considered private information. Some PLWHIV explained that they cautioned their spouse not to tell anybody else to avoid tarnishing their family name and exposing them to other people especially their in-laws. One respondent explained in response to what they consider private information, *"HIV-positive status, I cannot just disclose to anyone. It's my big secret because watanicheka, wanidharau (they will laugh at me and look down on me)"* (disclosed female). Information about one's HIV-positive status was considered private and not to be just disclosed to anyone. Most PLWHIV both disclosed and non-disclosed referred to it as "my biggest secret." For those who had disclosed, some often cautioned their spouse not to disclose to anyone else what now had become "our secret" to avoid tarnishing their family name and exposing them to other people especially their in-laws.

3.2 Finances

Majority of the respondents identified matters to do with certain details of their personal finances as private information. This information included the amount of money one has in their account(s); bank accounts one has; sources of money and personal identification numbers (PIN) for the Automated Teller Machine (ATM) and *Mpesa* (Mobile phone based money transfer). Most female respondents felt that information about their contributions to their *"merry go round", gitati or chama* (table banking) is private information.

3.3 Sexual Issues

Some respondents regarded information about their sexual experiences outside the marriage as private. A PLWHIV explained, *"What I consider private information is money issues, sexual issues and also if I have mpango wa kando (concurrent sexual partner), I think it is private"* (disclosed male). Another one said, *"my affairs outside marriage (concurrent sexual partners), I would tell God only"* (disclosed male). A female PLWHIV reported that she started being unfaithful when her spouse continued having extramarital affairs and this is information that she cannot share with her spouse. In response to what she considers private information, she explained, *"infidelity, when he started affairs outside our marriage, I had to look for a friend also, (laughs) boyfriend, such things I cannot share with him"* (disclosed female). Other issues that PLWHIV cited as private information include their future plans. A few respondents felt that they have no private information between them and their spouse especially after disclosing their HIV-positive status.

4. DISCUSSION

Information that was not considered private and easily discussed between most of the PLWHIV and their spouses mainly focused on issues perceived as obvious general discussions. The Social Penetration Theory (West and Turner, 2000, p.152) refers to such topics as issues on the outer layer, fairly general information which spouses felt the need to discuss. This is information which they do not mind the other spouse knowing.

McMaster's model of family functioning (Epstein, Bishop and Levin, 1978) note that family communication can be categorized into instrumental and affective communication. Affective communication involves the expression of feelings whereas instrumental relates to practical needs which arise within the family (Geldard & Geldard 2008, p.60). According to Barker and Chang (2013) instrumental communication concerns the ongoing of everyday activities in the family. Epstein et al. (2007) asserts that from experience families have difficulties with affective communication while functioning well in the area of instrumental communication.

The paper notes that one's HIV-positive status was considered private information by most of the PLWHIV and the privacy boundaries were tightly protected. Those who decided to reveal to their spouses chose to open their private boundaries and share their private information about the HIV-positive status with their spouses. This may be dependent on the perceived spousal communication behaviors as being supportive and the spouse providing physical or emotional support. The spouse was also trusted to keep the information confidential thus given access to the private information.

(Petronio, 2002) argues that once an individual is given access to one's private information, the owner relinquishes sole ownership of the information which is henceforth co-shared and collectively owned. Once the PLWHIV disclosed to their spouse and they co-share the information about the HIV-positive status, it shifted from "my secret" to "our secret". The spouse is expected to adhere to the privacy rules and keep the co-shared private information within the spousal boundary.

According to Bradshaw (1995, p.6), a secret maybe shared with no one else, or it may be known or confided to another person on the promise that the secret goes no further beyond the agreed upon boundary. Some PLWHIV had privacy management rules that reflect how they manage privacy and asked their spouses not to tell their secret to anyone else. This included rules that require family secrets to be kept confidential. This is also in line with Kikuyu culture as enshrined in proverbs such as *chira wa mucii ndumagirio kiharo* (Home affairs are not taken to the public square) Wambugu et al. (2006, p.224).

Among those PLWHIV who had not disclosed their HIV-positive status to their spouses, the HIV/AIDS topic was not discussed for fear that it could raise suspicion and thus kept secret. Muturi (2005, as cited in Chiao et al. 2009) concurs and says that the spousal communication remains limited among rural couples despite widespread dissemination of information on HIV/AIDS.

The non-disclosed PLWHIV generally avoided the topic and when discussed, they focused on the intention to get tested despite the fact that they had already tested and knew their HIV status to be positive. Petronio (1993, p.225) notes that people avoid certain topics due to several reasons. These include self-protection, relationship protection, partner unresponsiveness and social appropriateness. Also Afifi and Guerrero (2000, as cited in Petronio, 2002, p.50) suggest that "people avoid certain topics as a way to guard personal privacy boundaries either with the aim of developing the relationship or de-escalating it". They note that people refrain from disclosing issues that hamper their relationships and avoid discussing topics for fear of bringing up unpleasant issues. From the findings, all the PLWHIV who had not disclosed their HIV-positive status to their spouses avoided the topic of HIV/AIDS as a strategy to conceal their HIV-positive status.

The topic of HIV-positive status was private information for the non-disclosed PLWHIV. However, majority of the PLWHIV both disclosed and non-disclosed considered the following areas private and did not discuss them with their spouses. These include; "source" of HIV infection, past sexual history, *mpango wa kando* (concurrent sexual partners), amount of money one has and PIN numbers. Although the general topic of finances may be discussed, it is important to note that most PLWHIV reported not discussing the specifics of how much money one has in their accounts and the PIN numbers for bank accounts and *Mpesa* accounts.

From the topics considered private by the PLWHIV and not discussed with their spouses, three of them revolve around sexuality. The lack of discussion of HIV/AIDS also has a cultural dimension. Zulu and Chepngeno (2003) observed that most spouses avoided the topic of HIV/AIDS. According to Bradshaw (1995, p.13), HIV/AIDS touches on areas that he refers to as areas of natural concealment that belong to the realm of the private, which entail taboo topics and secrecy in most communities.

Fapohunda and Rutenberg (1999) state that culturally in most Kenyan societies, sexual issues were almost always taboo topics and were never discussed among men and women irrespective of marital status. There is what they call a culture of silence on sexuality. Sex in most African communities is a taboo subject, it forms a part of language and our existence that people do not just talk about, it just happens. In their study, respondents said that they discuss respectable issues not unconventional issues like sexual matters.

Baxter and Wilmont (1985, as cited in Petronio, 2002, p.103) identify six topics that were off limits for people in opposite sex relationships. They list; extra-marital activities, relationship norms of behavior in the relationship itself, prior relationships, conflict inducing topics and negatively valenced disclosures about the self.

Muturi (2005, as cited in Chiao et al. 2009) argue that poor spousal communication may result from social and cultural norms that create gender imbalances where mostly it is the men who are in dominant positions relative to the women. These gender imbalances can affect the extent of sexual negotiations and behaviors. Lucchetti (1999) states that, "engaging in safe sex is a goal for many relational partners but being open and honest about one's sexual history may harm a developing relationship making both men and women reluctant to discuss their sexual experiences with potential lovers". Individuals, both men and women need to take responsibility for their own health by asking questions relating to safer sex and protection against HIV infection. Partners especially women can be equipped with assertive skills to allow them ask and negotiate for their reproductive health rights.

This may point to the need for HIV program managers to develop interventions that would encourage spouses to talk not just about HIV/AIDS but on issues relating to their reproductive health. Some studies indicate that when couples talk, the uptake of family planning increases. Ogunjuyigbe et al. (2009) showed that marital partners who discuss on whether to delay or stop childbearing and are more likely to use contraceptives than those who have not discussed the issue. Sheriff (2012) found that contraceptive use increased with increased communication between couples.

A HIV-positive status is highly private information that individuals go to great lengths to protect. Most PLWHIV tightly guarded their private information about their HIV-positive status whether by keeping it a secret to themselves or between the PLWHIV and their spouse. This helps the PLWHIV maintain face in the community. Concealing one's HIV-positive status helps them to self-protect against stigma, rejection and gossip. This is in line with Benoit (1995, as cited in Pearson & Nelson, 2003) argument that people engage in communication behaviors designed to reduce, redress or avoid damage to their reputation.

From the study we established that PLWHIV can open up to allow disclosure thus increasing the collective boundary area if certain conditions are met. The two pre-requisite conditions for disclosure were trust and support. Spouses who were perceived as trustworthy by the PLWHIV to keep their private information about their HIV-positive status confidential or were able to offer support to the PLWHIV were given access to their private information. This could either be physical, financial, emotional or psychological support. Stewart (2002, p.302) says that "trust is the essence of which emotional safety serves as the foundation for self-disclosure because trust enables you to put your deepest feelings and fears in the palms of your partner's hands, knowing they will be handled with care".

5. CONCLUSION

The paper notes that although certain topics are generally discussed between PLWHIV and their spouses such as farm development and family welfare, there are other topics that most PLWHIV consider private information and thus kept secret. Their HIV-positive status information is believed to belong to them alone and it is not to be shared even with the spouse. Where a PLWHIV chooses to disclose, the paper concludes that trust and support are important in the decision as to whether to reveal or conceal the secret of one's HIV-positive status.

Program developers in the field of HIV/AIDS can design communication strategies to help spouses develop and improve communication behaviors that create a safe supportive environment to promote openness in communication and facilitate disclosure of HIV positive status. There is thus need to organize forums in the community where couples can discuss issues about sexuality, HIV/AIDS, the need to know one's HIV status and disclose to the spouse and other family related issues.

The study recommends that HIV/AIDS prevention strategies should include empowerment programs which can equip the individuals especially women with the necessary skills to gain self-confidence and feel empowered to seek information and make personal choices to protect themselves from HIV/AIDS. This may include skills such as assertiveness training, income generating activities to empower the PLWHIV economically especially the women and negotiation skills such as negotiating for condom use and seeking information from their spouses.

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