Which way to Tell? Methods of Disclosure among People Living with HIV to their Spouses in Kirinyaga County, Kenya

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ABSTRACT

The paper presents methods of disclosure of HIV-positive status to spouses of people living with HIV in Kirinyaga County, in Kenya. Disclosure of a HIV-positive status is an important tool for prevention of HIV and to access treatment, support and care yet many people who know their status do not disclose to their spouse or sexual partners. The people living with HIV knew that they needed to disclose their HIV positive status to their spouses, the big challenge was how? The paper gathers information from a larger qualitative study that investigated factors influencing disclosure among people living with HIV to their spouses in Kirinyaga County. Data was collected from a convenience sample of both men and women living with HIV using semi-structured In-Depth interviews. The paper found that most disclosed indirectly using what was referred to as the "pretend method", where the person living with HIV pretended that they had not tested and requested the spouse to go for HIV testing. Other methods included the use of a third party, questions, nonverbal disclosure and use of humour. The paper concludes that most people living with HIV disclosed indirectly which helped them reduce the risks of a direct face-to-face disclosure. The study recommends that couple HIV testing and counselling and partner notification should be encouraged to ease the process of disclosure.

Key Words: HIV disclosure, Methods of disclosure, People living with HIV, Spouses.

INTRODUCTION

UNAIDS (2019) indicates that in 2018 there were 37.9 million people living with HIV globally with 1.7 million people newly infected with HIV in the same year. NACC (2018) indicates that there were about 1,388,169 million people living with HIV in 2017 and approximately 52,800 new infections in Kenya. Kirinyaga County had a total of 13,893 people living with HIV in the same year.

NACC and NASCOP (2012) observe that heterosexual sex accounts for 77% of new infections and adults in stable seemingly low risk heterosexual relationships make up the largest share of new HIV infections. 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, however 46.4% of them reported not knowing the HIV status of their most recent sexual partner.

Disclosure is one of the fundamental ways of making one's information known to others. Pearson, Nelson, Titsworth & Harter (2003) define Self-disclosure 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". According to WHO (2019), "disclosure of HIV status is an important part of the process of living with HIV and is crucial to continuum of HIV care". Serovich and Mosack (2003) note that "disclosure of HIV status is important because it permits the partners to be included in the decision making process in either allowing or not allowing unsafe behaviour to occur. Petronio et al. (1993) explains that couples use explicit and implicit strategies to communicate private information. Explicit strategies are said to be direct and unambiguous and the message content is clearly articulated while implicit strategies are indirect.

Talking about sex especially across genders is a complex issue in many African societies. Discussion of sex and sexuality openly is viewed as taboo and vulgar as cultural constraints limit discussion about sex. Schatz (2002, as cited in Zulu & Chepngeno 2003) state that "couples may avoid direct verbal communication if one or both of them perceive the topic of HIV prevention so sensitive that to broach it would threaten the tranquillity of the marriage". Despite these constrains, spouses including people living with HIV find alternative ways to communicate their status to their spouses. Dodoo et al. (2000) argues that, "although direct discussion between reproductive partners may not occur, there is room for ideas to be communicated from one spouse to the other, the playing of certain music, the wearing of specific waist beads, certain demeanours and even the cooking of favourite meals may all convey clear unambiguous sex related messages to a partner". Zulu and Chepngeno (ibid.) found that husbands and wives use subtle and gendered strategies to communicate. For instance in an attempt to encourage fidelity, one spouse may talk about the effects of HIV/AIDS on their children or illness or death of a friend or neighbor.

Catania et al. (1989, as cited in, Chiao et al. 2009) state that a HIV-positive person knows exactly what they need to do, that is to notify their partner, not to have unprotected sex and to use a condom. But the challenge is how to disclose this information about their HIV-positive status to their spouse. The people living with HIV reported being aware of the need to disclose and majority had been told by the HIV Counselling and Testing service provider to inform their spouses, the question of how to disclose was one that majority had to deal with. It is against this background that this paper focuses on methods of disclosure among people living with HIV in Kirinyaga County in Kenya.

RESULTS AND DISCUSSION

People living with HIV reported different methods of direct and indirect disclosure of their HIV-positive status. These included direct face-to-face disclosure, use of questions, third party, humour and leaving clues such as the clinic card and medication.

Direct Disclosure

Some people living with HIV reported disclosing their HIV-positive status to their spouses in a direct face-to-face encounter. In this case the information about one's HIV-positive status was overtly conveyed to the spouse either verbally in a face-to-face interaction or in a few cases via telephone. The use of direct disclosure was influenced by three factors namely; the HIV Counselling and Testing service provider advice; the spouse having prior knowledge of the illness of the person living with HIV or having sought a HIV test and anger.

Face-to-face

Face-to-face disclosure entails an overt direct verbal message informing the spouse that one is HIV-positive. Most People living with HIV who disclosed directly face-to-face said that they were advised to disclose to their spouses by the HIV Counselling and Testing service provider. As one explained their adherence to the advice, *"After supper, I obeyed what the doctor had told me. I approached him and told him that I had tested positive, despite fearing being beaten or being blamed that I had brought the virus into the house, I disclosed to him"* (disclosed female). Others disclosed for fear that the service provider would inform the spouse or for fear of infecting the spouse and hence decided to disclose directly face-to-face. A respondent disclosed directly believing that the service provider would call the spouse if he did not disclose. He explains, *"I just told her that I went to the hospital and I was told that I needed to be tested for HIV, and I tested positive therefore she should also go for the test. Again the counsellor had asked for her telephone number so that if I did not disclose she would be called on phone"* (disclosed male).

A person living with HIV whose spouse had persistently been asking her to go for HIV testing due to her ill health pointed out how she disclosed. *"I did it face-to- face as he used to keep on insisting that I get tested. Therefore I took the advantage and sat with him and later revealed the big secret to him"* (disclosed female).

For those whose spouses knew that they had an illness of one kind or another, the "known illness" gave them a starting point to disclose. Such illness included T.B., chest, uterus or stomach problems. Other factors that helped the people living with HIV to disclose face- to-face to their spouse was that the spouse had accompanied them to the hospital, or the couple had talked about the need to go for a HIV test before. These factors provided them with an opportunity to give feedback about the HIV test results, the hospital visit or what the doctor had told them. Some of those who disclosed directly reported being sickly and in some cases their spouses were also sick. The stage of illness was a motivator for disclosure either to access health care, support or for others to get their spouses tested (Petronio, 2002; Greene et al. 2003).

Others especially women who believed that their spouses had infected them disclosed directly driven by anger. One who believed that the spouse had infected her with HIV explained, *"I disclosed to him directly because he is the one who was there when I was discharged. Again he is the one who infected me. He is the one who is unfaithful"* (disclosed female). Another explained, *"I asked him whether he had slept with any other woman to which he said yes. Out of anger I told him I was HIV-positive and he is the one who infected me"* (disclosed female). Stiles (1987, as cited in Vangelisti, 2004) found that catharsis was a primary motivator for disclosure. Some psychologists believe that cathartic disclosure has real healing power physically as well as psychologically. Corey (1995) notes that disclosure can be therapeutic in itself as it releases energy that has been used to withhold threatening information. This emotional release normally leaves a person feeling freer.

Some people living with HIV expressed the view that disclosure required a suitable moment. These included "briefing talks" where ones asks the spouse about their day or business, taking the spouse out for dinner and making the evening jovial. They attempt to create an environment which would facilitate open communication and ease disclosure as one explained, *"I took him out to dinner, I sweet talked him and I told him in a cunning way that I had tested HIV- positive"* (disclosed female). Serovich et al. (2005) observed that direct disclosure was easier with light moments such as dinner. Picking the appropriate moment and talking helped ease the disclosure process. Petronio (2002) suggests that the social environment and physical setting can influence disclosure.

Telephone

Most of the People living with HIV who reported disclosing directly used face-to-face disclosure. However some called their spouses and disclosed on telephone. This was the case where the spouse lived far from home and they could not wait till the spouse came home for the weekend or they were so angry to wait to get home. One described how they disclosed, *"I was so angry, I called him from the hospital where I was tested and informed him of my status"* Literature on sharing and telling bad news shows that it is never an easy thing. Affleck (1999) notes that it is easier to give bad news through electronic mail than face to face as one does not have to "sugar coat" the information or face the recipient, which is stressful. The use of the telephone by some people living with HIV creates that spatial distance and relative safety and also provides cathartic relief.

Indirect Disclosure of HIV-Positive Status

People living with HIV also used indirect strategies to disclose. Tesser, Rosen and Tesser (1971, as cited in Baile et al. 2000) noted that the bearer of bad news often experiences strong emotions for the news and fear of negative evaluation. The stress creates a reluctance to deliver the bad news which they named the "MUM" effect. This may explain why majority of the people living with HIV reported disclosing indirectly to avoid the potential risks of a direct face-to-face disclosure such as physical violence and rejection.

Using indirect strategies allows the people living with HIV to have several options and enables them to save face. They do not have to face the spouse with the information about their HIV-positive status (Petronio, 2002). Indirect disclosure allows them to "test the waters" before deciding whether to disclose or not. Petronio (ibid) explains that "individuals can use incremental disclosure where they can "test the waters" before actually disclosing".

The lack of discussion of HIV/AIDS has a cultural dimension. 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. Their respondents reported discussing respectable issues and not issues like sexual matters. FHI (2002) explain that "in some cultural settings, increased partner communication about sexuality may disrupt power imbalances in intimate relationships, leading to marital discord, suspicions of infidelity and even partner violence". A HIV-positive status is highly private information and people living with HIV go to great lengths to guard and protect it from others (Greene et al. 2003). These factors may explain why some spouses may avoid topics around sexuality including HIV/AIDS and when they communicate they may do so indirectly. Various methods were cited including: the "pretend method"; giving the spouse a condom; introducing the topic of HIV/AIDS and importance of knowing one's HIV status; placing the clinic card at a place the spouse could locate; or telling a third party to disclose to one's spouse.

The "Pretend" Method

The most commonly used indirect method of disclosure was for the people living with HIV to pretend that they had not been tested and then request their spouse to accompany them to the health facility for a HIV test. Some reported telling their spouses that the doctor wanted to see both of them at the hospital. This was easier for those who knew that their spouses were sick. One explained how they disclosed, *"I disclosed to my wife by telling her that we needed to be tested, when we went for the test, I pretended not to have been tested previously and we saw each other's results"* (disclosed male). This method was said to be commonly advised by the HIV Counselling and Testing service providers as confirmed by a Key Informant who said, *"We try very much to talk to the ones who are HIV-positive on the need to disclose to avoid infecting their partner. We incorporate certain tricks such as assuming that one has never tested assisted disclosure"*.

Role Play

Role play was used by some key Informants to guide the People living with HIV on how to disclose to their spouses. One described the process, *"We tell them to pretend that they have never tested and we introduce couple counselling. Also we use role play, I take the role of a wife and they take the role of the husband and vice versa. This builds the disclosure skills and it encourages those unable to disclose to be able to disclose"* (clinical officer). Role plays help to build their confidence and facilitate disclosure.

Third Party

People living with HIV also disclosed indirectly through the use of a third party. The most commonly reported confidante of a HIV-positive status disclosure was a mother, followed by sister, children especially the eldest and friends in that order of priority. Other confidants included brother, parents, HIV support group members and church pastor. The reasons given for disclosing to these individuals varied from physical, financial, emotional and psychological support. For instance one who had disclosed to her daughter said, *"I disclosed to my daughter (probe, why?), I wanted her to know that I am HIV-positive and that I may not live long. So in case of anything she can take care of the other children"* (non-disclosed female). Some of them used the confidants to disclose to their spouse. One reported disclosing to a sister-in-law first as she explained, *"I told him through the mother, after one week (after the HIV test), I sent my sister-in-law to inform my mother-in-law to tell the son (my husband)"* (disclosed female).

The use of a third party is a commonly used strategy in the traditional set up to convey information, negotiate and resolve conflict in most Kenyan communities. Wolf and Blanc (2000, as cited in, FHI, 2002) suggest that, "Because direct communication can generate conflict, it might be best to first promote direct discussions of such sensitive topics by having someone outside of the couple raise them in a public forum". Among the Kikuyu of Central Kenya where the study was done, a young man wishing to marry asked for the girl's and her family's approval through elders not directly. The marriage which was a long complex process involved not only the bride and groom but also their friends, the village and the groom's father and friends (Wambugu et al. 2006, p.115). Many people living with HIV had disclosed their status to a third party including those who had not disclosed to their spouses, however the confidant was often asked to keep the information confidential to avoid gossip or being stigmatized. Being a familiar method in the cultural set up, it can be positioned as an option for disclosure during HIV Counselling and Testing and in the HIV support groups.

Questions

Another indirect strategy used by the People living with HIV to disclose was the use of questions. Questions were asked to avoid, pre-empt, clarify or respond to questions from a spouse. Others were asked to "test the waters" and assess a possible reaction from the spouse. Some would first enquire for certain information from a spouse or give information about their visit to the hospital. A respondent narrated his disclosure experience: *"I started by questioning her on what she would do if she found out that she is HIV-positive. She said that she would take drugs like other people. I then asked her if she knows other people who were taking drugs and she said yes, she knows. Then I requested her if we can get tested together to which she agreed and we went for the HIV test"* (disclosed male).

Adams (2009) notes that, "interpersonal questions are powerful tools and can be used for speaking and communicating with others, internal questions for reflection, thinking, learning and problem solving". Berger and Calabrese in their Uncertainty Reduction Theory postulate that individuals have a need to reduce uncertainty about others by gaining information about them (West and

Turner, 2000). A person living with HIV who asks the spouse "what would you do if I tested HIV-positive?" wants to reduce the uncertainty and get answers or clarification to their many unanswered questions. In addition to reducing uncertainty and tension, other questions were used to "test the waters". They help the person living with HIV to assess the spouse's possible reaction if they decided to disclose. In asking questions, the person living with HIV wants to hear what their spouse thinks and their attitude towards people who are HIV-positive. This would either facilitate disclosure or withholding of their HIV-positive information.

Non-verbal Cues

Some people living with HIV disclosed indirectly using non-verbal strategies. These included using non-verbal cues such as placing the hospital card at a place the spouse could easily locate; giving the spouse a condom when requested for sex or refusing to have sex. One explained, "*When I arrived home, I placed the CCC(Comprehensive care Centre) card on the table, after he read it, I asked him what he wanted to do with me, but he just said that he will also go and get tested"* (disclosed female).

The use of non-verbal strategies gives the people living with HIV options to be vague about their HIV-positive status. According to Petronio (2002) "being vague about disclosure of private information to save face allows the disclosing individual the ability to control the amount, depth, breath of information disclosed". Driskell, Salomon, and Safren (2008) observed that using a condom can be disclosure without even saying it. Bird and Voisin (2010) found that among men who have sex with men they leave nonverbal cues such as medicine bottles and exposing HIV-positive tattoos. This strategy forewarns any potential sexual partner and this way they do not have to talk about their HIV-positive status. Gamble and Gamble (2002) indicate that "in a normal conversation verbal channel carries less than 35% of the actual meaning of a message and 65% of the message is communicated non-verbally". This may point to a need for policy makers and HIV program managers to promote nonverbal disclosure among people living with HIV who find it difficult to disclose verbally. Insisting on safer sex, refusing to have sex or leaving drugs around may be a safer way for them to disclose their HIV-positive status.

Use of Humour and Metaphors

Some of the people living with HIV used metaphors, humour and jokes. One compared disclosure to *"a burning charcoal on my head"*. One can only imagine how hot a piece of burning charcoal can be and it needed to be dropped before it could burn them. Another one used the Kiswahili saying, "*yakimwagika hayazoleki (once water has spilled, you cannot collect it). So I had no option but to tell him (pause) and then again he is the only one for me and we share our problems together"* (disclosed female). Another used the analogy of belonging to the same feather. He said, *"Because we are of the same feather, we are both HIV-positive"* (disclosed male).

Humour, jokes metaphors help to reduce anxiety and to gain courage to disclose. HIV/AIDS is no laughing matter or joke and although a weighty issue, they created a light moment about a difficult subject in a light-hearted manner by using humour. Berk (2003, as cited in, Stambor, 2006) says that humour helps relieve fear and reduce anxiety. Deiter (1998) suggests that humour has various physiological and psychological benefits such as putting us at ease; helping us to relax and helping us see life from a different perspective. Humour use has been recognised as one of the coping mechanisms people use to deal with unfortunate life conditions (Vaillant 1977, as cited in, Barbato et al.1997). Through humour, people share their experiences with others and realise that they are not unique and at times not as badly off as they think. Civikly (1989, as cited in, Barbato et al. ibid.) notes that individuals use humour as an indirect way of communicating and more specifically as a

means of communicating difficult information. He adds that some information may be considered inappropriate if it is not disclosed in a humorous fashion.

Humour was used to create an environment which would make it easier for them to disclose. One described how he prepared himself for disclosure. He narrated, *"It was hard for me but I was really encouraged by the health care providers and I was prepared for anything. I made the evening jovial and generated open communication. I accepted a joke from the whole issue because to realise that she had kept it a secret for some time without really revealing to me. She had known her HIV-positive status and started attending clinic. So you can be a hypocrite for all that long?"* (disclosed male).

CONCLUSION AND RECOMMENDATIONS

Most people living with HIV even those who had disclosed their HIV-positive status expressed difficulty in disclosing. However those who decided to reveal their HIV-positive status to their spouses used various direct and indirect methods. This difficulty points to the need for people living with HIV to be properly equipped with disclosure skills in HIV Counselling and Testing sessions and HIV support groups to facilitate disclosure. There is need for more trained counsellors and refresher courses for the existing ones who need to be equipped with the necessary disclosure skills to facilitate disclosure among people living with HIV. Couple HIV Testing and Counselling should be encouraged as only two people living with HIV reported couple counselling. Also the option of Partner notification should be explored with the people living with HIV. Since majority of them disclosed indirectly, there is need to explore expressive mediums of communication that could facilitate disclosure such as art therapy and play therapy.

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