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Disclosing HIV-Positive Status: What Do Questions Have to Do with It?

¹Kiranga, Jacinta Wanjiku; ²Lumala, Masibo F. P.

Department of Communication Studies.

Moi University, P.O. Box 3900-30100, Eldoret

Email: 1jkiranga@uonbi.ac.ke; 2masibo@gmail.com

Richard, Musebe

Department of Development Studies.

Moi University, P.O. Box 3900-30100, Eldoret

Email: musebe@mu.ac.ke

Abstract

This article discussed the need to ask questions among people living with HIV to facilitate disclosure. This is because disclosure of a HIV-positive status is an important tool for prevention of HIV and early treatment, many people who know their status do not disclose to their spouse or sexual partners. Disclosure would not only protect the spouse from risk of infection and if already infected be able to access treatment, support and care but also promote adherence to antiretroviral therapy. The paper looked at questioning as an important communication skill that can facilitate disclosure. This paper is based on a larger qualitative study that investigated the factors influencing disclosure of HIV-positive status to spouses among people living with HIV in Kirinyaga County in Kenya. Data was collected using semi-structured In-Depth Interviews. The paper argued that questions play a crucial role in disclosure of a HIV-positive status in accessing information which would otherwise be unavailable about the HIV-positive status of their spouses and suggests incorporation of communication skills on questioning and disclosure at the comprehensive care Centre services.

Key Words: HIV disclosure, person living with HIV, questioning, spouses, psychological safety

Introduction

HIV/AIDS is a major health and development problem in Kenya. In 2017, there were about 1.5 million people living with HIV and approximately 52,800 new infections in Kenya with

Kirinyaga having a total of 13,893 people living with HIV (Kenya HIV Estimates Report, 2018). These figures indicate that we are still far from achieving the HIV global targets of Zero new infections.

KAIS (2012) indicates that heterosexual sex within a union or regular partner accounts for 44.1% of new HIV infections and that among married or cohabiting partnerships, 4.8% are HIV discordant. NACC (HIV AND AIDS Profile: Kirinyaga County) notes that 73% of those testing for HIV in Kirinyaga County delayed before joining a care and treatment program hence exposing the spouse to the risk of HIV infection if not already infected. There is need to address ways to reduce infection among the discordant couples.

Disclosure of HIV-positive status remains an important tool for prevention of new infections and early treatment for HIV-positive individuals. HIV status disclosure is “an important part of the process of living with HIV and is crucial to continuum of HIV care” (WHO, 2019). Disclosure of HIV status reduces HIV/AIDS transmission as it may result in safer sex interventions such as condom use and adherence to Antiretroviral Therapy.

Many individuals infected with the virus and know their HIV status do not disclose this information 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 partner, however 46.4% of them reported not knowing the HIV status of their most recent sexual partner. This exposes the PLWHIV's spouses to the risk of HIV infection. People living with HIV avoid disclosure due to stigma, fear of rejection, blame and being labeled as immoral. Fear and stigma discourage people living with HIV from disclosing their status to their family members and sexual partners undermining their ability and willingness to access and adhere to treatment (UNAIDS 2014).

Driskell, Salamon and Safren (2008) noted that “many people are unaware of their partners status and make assumptions that they are not at risk for HIV infection because they are married, in relationship, their partner looks healthy or simply because their partner did not use a condom”. Research shows that people are often more comfortable disclosing or practicing safer sex with partners outside their main relationship. KAIS (2012) indicated that condom use with sexual partners of unknown HIV status in the last twelve months was low, highest among casual and other partners and lowest among married and cohabiting partners.

If people living with HIV do not disclose or disclose long after, how else can their spouses and sexual partners access information about their HIV-positive status? Looking at the Johari Window (Tubbs, 2001) disclosure helps to move the HIV-positive status information from the hidden to the open area which is crucial for HIV risk reduction and access to treatment, care and support. It is against this background that this paper discusses the use of questions in HIV disclosure. The paper argues that questions can facilitate disclosure of one's HIV-positive status information, a crucial tool for HIV prevention.

Methodology

The paper is part of a larger research that adopted a qualitative approach. It was conducted in Kirinyaga County in Kenya. The sample consisted of both male and female people living with HIV attending selected Comprehensive Care Centres in the County. Data was collected from a convenience sample of 98 people living with HIV and seven key informants using semi-structured In-depth interviews. The data was analysed thematically.

Results and Discussion

As teachers, we have not only come to appreciate the role of questioning in the classroom but more important the type of questions and how they are asked can either lead to further discussion and a deeper understanding and critique of an issue or the end of discussion. Most modern-day innovations and scientific discoveries started with a question. Socrates is known for having used questions to simulate debate and critical thinking among his students aimed at a deeper understanding of phenomenon. Socratic questioning is a skill still advocated as a powerful contemporary teaching method (Brill & Yarden, 2003, as cited in, Vale, 2013). Asking a question often leads to further questions that dig deeper into a phenomenon gaining further insights and shared understanding.

Why the Questions?

Questions are not only important in the classroom but also important at interpersonal communication level. Adams (2009) believed 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”. Questions can enhance understanding since the questioning is likely to increase disclosure and learning necessary for understanding. It can also result in validating and showing concern (Reis and Patrick (1996, as cited in Huang et al. 2017). Questions also play a key role in counselling approaches in helping the client move towards a better understanding of their issues and to take action towards a solution or creating awareness.

A lot of questions and uncertainties are associated with HIV/AIDS. One way to gather information and reduce uncertainty is via asking questions. 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 & Turner, 2000). A spouse who asks a person living with HIV the following questions wants to reduce the uncertainty and get answers or clarification to their many unanswered questions which they now voice.

1. What did the doctor say?
2. How do you feel?
3. I see you swallow drugs often, is there a problem?
4. Why do you need to go to the hospital often?
5. Why are you admitted at the hospital so frequently?

Suspicion could also elicit such questions. If an individual complains of one illness after another having sought treatment from various health facilities or is frequently on medication, the spouse is bound to be suspicious and seek answers. Others were suspicious of the “tablets” the person living with HIV was taking and why they took them.

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. Such questions include the following.

1. What would you do if I tested HIV-positive?
2. What would you do if you tested HIV-positive?
3. Do you know anyone who is HIV-positive?

This kind of question allows the person living with HIV to make a choice on whether to disclose or not. Petronio (2002) explained that “individuals can use incremental disclosure where they can “test the waters” before actually disclosing”. The choice to share or keep private information hinges on a risk-benefit ratio for those involved (Petronio (ibid.)). Each option has benefits and costs such as care and support versus stigma, rejection and violence to just name a few. Hence the need for a “*dipstick*” question to check the safety necessary for disclosure.

Some spouses asked questions to seek clarification or dispel rumours that one is HIV-positive or their former spouse or *mpangowakando* (concurrent sexual partner) unknown to the spouse had died of HIV. International Peacebuilding Advisory Team (2015) suggested that “almost all questions have assumptions built in them. Some assume a solution, error, blame which may either lead to defensiveness or stimulate reflection, creativity and/or collaboration among those involved”. A person living with HIV who asks the spouse, “*have you ever slept with another woman?*” is apportioning blame to the spouse for their HIV-positive status and for “*bringing the virus home*”.

Other spouses used questions to seek clarification as to why they needed to use condoms. Most people living with HIV had difficulties introducing condoms to their spouses despite having been advised by the HIV counselling and testing service providers to use them. When requested to have sex, some gave the spouse a condom. The common question was, “*why do we need to use the condom?*” especially for those who had not been using them before. It is especially difficult for women to ask their spouses to use condoms. Catania (1992, as cited in, Chiao, et al. 2009) noted that if women believe that safe sex negotiation will cause conflict, they may avoid the issue.

Some people living with HIV used self-interrogation questions which help with self-reflection. In the following questions, the person living with HIV asks themselves hard questions which they need to answer by either disclosing or concealing their HIV-positive status.

1. How will I take my ARVs without my spouse asking questions?
2. How will I avoid breastfeeding without raising suspicion?
3. How will I introduce condoms?

Self-reflection helps to build self-awareness. As one asks themselves questions, they gain a better understanding of their situation, their feelings and their thoughts. John Maxwell in his book “*The 15 invaluable Laws of Growth*” discusses the law of reflection. He argues that we need to ask ourselves tough questions on a daily basis to improve our lives and take action based on insights from the self-reflection. Rogers (1961) believed that the only way to grow and heal is by increasing our self-awareness.

Outcomes of the Questions

The way a question is asked or worded can influence the response. Pearson and Nelson (1997) argued that “supportive and defensive climates are created by what people say and how they say it”. A question that is perceived as non-threatening and the spouse experiences support is likely to yield disclosure. Such questions can enhance understanding since the questioning is likely to increase disclosure and learning necessary for understanding. It can also result in validating and showing concern (Reis & Patrick (1996, as cited in Huang et al. 2017).

A question like, “*why not go for a HIV test?*” after a couple had done several diagnostic tests and still not sure of the problem and the spouse is perceived to be concerned and non-judgmental, was likely to result in disclosure. This was especially where the spouse accompanies the person living with HIV to hospital or supports them when sick for instance by making porridge for them. Most people living with HIV reported disclosing to their spouse or other confidante because they trusted them to keep their secret safe and perceived them to be good listeners, understanding and supportive. This echoes Rogers (1961) assertion that individuals will only self-disclose if they feel psychologically safe in the relationship and experience the core conditions of empathy, unconditional positive regard and genuineness.

In some instances, questioning in a non-defensive way resulted in reciprocal disclosure where a spouse who had previously concealed their HIV-positive status also finds it safe to disclose. Other spouses also opted to go for a HIV test. Gamble & Gamble (2002) suggested that, “when one takes the risk to reveal feelings to others, the relationship is likely to reap definite benefits such as making it less threatening for the other person to reveal their feelings”. By being transparent we create a safe atmosphere for others to respond in kind (Griffin, 2000). Those who disclosed found it easier to adhere to antiretroviral adherence since they do not have to hide medications or only take them when the spouse is away. Strict adherence to antiretroviral therapy can reduce the risk of sexually transmitted HIV (Cohen, Chen, McCauley et al. 2011).

On the other hand, if a listener perceives a question as threatening, the individual may become defensive and even conceal information about their HIV-positive status. A person living with HIV whose spouse talks negatively about HIV-positive persons is likely to respond in a manner that does not stigmatize them further and expose them to other risks. These include security, stigma, face, relational and role risks (Petronio, 2002). Lane and Wegner (1995, as cited in Petronio, *ibid.*) observed “that people keep secrets because there is a fear of the real or imagined repercussions the hidden information could bring with exposure”. Most people living with HIV referred to their HIV-positive status as “*my secret*” or “*my biggest secret*” which points to the level of secrecy around it. They may lie as a way to protect their “secret” which has a potential to destroy them if it becomes known. They may lie as a way to protect their “secret” which has a potential to destroy them if it becomes known. Even those who had disclosed to their spouses often cautioned them to keep the information secret within the spousal boundary to avoid stigma and tarnishing their name. People lie for protection and the “ability to keep things secret is an essential power that all human beings possess in order to protect themselves” (Bradshaw, 1995). Most non-disclosed individuals reported lying that they were seeking treatment for stomach or chest problems or gynaecological problems for some women. These usually were illnesses that their spouses knew about and helped to keep their HIV-positive secret safe.

Some people living with HIV who had not disclosed reported that they could disclose if their spouses started being supportive by caring about what the family eat; if the spouse started listening or stopped blaming and being violent. Some expressed feeling guilty by concealing their HIV-positive status from the spouse. Gamble & Gamble (2000) noted that concealing the HIV-positive status may result in “stress, shorter lifespan, personal and interpersonal difficulties” In such cases, the lack of psychological safety created by the blaming and lack of care hindered disclosure. When members attack and judge each other they create a defensive climate (Pearson and Nelson 1997). The fear of stigma contributes to people living with HIV setting up defensive boundaries around their private information and concealing their HIV-positive status (Greene et al. 2003). Lying about one’s HIV-positive status by concealing the information helps individuals “to manage what we perceive to be difficult situations,

situations that make us more vulnerable than we would like to be” (Camden et al. 1984, as cited in, Gamble & Gamble, 2000). 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 *ibid.*).

Why Are They Not Asking Questions?

Asking questions is one way to get HIV disclosure information, however individuals may not ask questions. Asking questions and discussing the subject of HIV/AIDS is often faced with challenges which hinder asking questions between people living with HIV and their spouses. One challenge has to do with HIV/ADS being associated with the subject of sex and sexuality making it a difficult subject for most individuals. Lucchetti (1999) argued that “people often do not ask questions about their sexual experiences and history as this may harm the relationship”. Certain topics are difficult to talk about for cultural and social factors (Bradshaw, 1995). In Kenya TV programs and films perceived to carry sexual connotations are often banned. For instance, in 2017, the Kenya Film Classification Board Chief Executive banned the film *Rafiki* due to what was termed as having a homosexual theme. Klitzman and Bayer (2005) asserted that HIV disclosure revolves around moral, social and psychological decision making forcing the people living with HIV to confront rarely discussed issues about truth, lies, sex and trust.

Talking about sex especially across genders is a complex issue in many African societies where discussion of sex and sexuality openly is viewed as taboo and vulgar. Zulu and Chepngeno (2003) found that husbands and wives in rural Malawi use subtle and gendered strategies to communicate. It is especially difficult for women to initiate discussion and ask their spouses questions for instance to use condoms. Some people living with HIV opted to conceal their HIV-positive status or avoid the topic. Cultural norms prevent women from initiating talk on sexual matters with husbands for fear of suspicion of infidelity (Cau&Agadjanian, 2008). Catania (1992, as cited in, Chiao, et al. 2009) asserted that if women believe that safe sex negotiation will cause conflict, they may avoid the issue.

Huang et al. (2017) suggested that some people may want to ask a question but are not sure of which questions to ask or worry that their questions may be perceived rude, intrusive or inappropriate questions. HIV is highly private and some questions may be perceived as intruding on one’s privacy. Such disclosure issues can best be addressed in a therapeutic setting to avoid more harm to the person living with HIV. Most people living with HIV reported being referred to as “*immoral*” a stigmatizing label. Questions may raise suspicion and expose them to further stigma.

Conclusion and Recommendations

Questions play a crucial role in HIV-positive status disclosure. It can also result in the spouse of a person living with HIV disclosing a previously concealed HIV-positive status and for others going for a HIV test to know their HIV status. These are crucial for HIV risk reduction and prevention since those who disclose find it easier to introduce safer sex and adhere to antiretroviral therapy. People living with HIV can be encouraged to disclose as well as ask their spouses their HIV status and other questions relating to safer sex and HIV prevention.

Questions do not always result in disclosure as discussed above but are crucial to providing disclosure information. I suggest that HIV/AIDS programs should incorporate communication skills on questioning and other disclosure skills that would empower PLWHIV and spouses to seek information from each other on HIV/AIDS. This can be incorporated as part of the Comprehensive Care Centers services where the people living with HIV seek treatment, care and support. I would also recommend assisted disclosure where any questions or issues that

the people living with HIV and their spouses have withheld can be dealt with in a safe therapeutic environment.

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