

FACTORS INFLUENCING DISCLOSURE OF HIV STATUS TO SEXUAL PARTNERS IN BOTSWANA

T.K. Masupe, MPH graduate
University of South Africa
Department of Health Studies

G.H. van Rensburg, D Littet Phil
University of South Africa
Department of Health Studies
Corresponding author: vrensg@unisa.ac.za

S.P. Human, D Cur
University of South Africa
Department of Health Studies

ABSTRACT

Disclosure of one's Human Immunodeficiency Virus (HIV) status to a sexual partner has increasingly gained prominence in the management of the HIV/AIDS pandemic. Policies are based on the premise that if those infected with HIV disclose their status, it will lead to safer sex and therefore reduced rates of HIV transmission.

A qualitative study, utilising in-depth interviews, was conducted to explore and describe the factors influencing the disclosure of persons' positive HIV status to their sexual partners in Botswana.

The major findings of the study confirmed that disclosure is a multi-staged process. People infected with HIV experienced mainly positive, but also some negative, consequences following disclosure. Such experiences were associated with the disclosers' motivations, personal and cultural beliefs, risk-benefit assessments, individual circumstances (contexts), previous experiences, and perceived degrees of control over private information.

The Communication Privacy Management (CPM) Theory helped to understand the decision to disclose private information. The key factor influencing disclosure within this theory was protecting others.

Recommendations address the privacy rule management criteria to deal with disclosure of sensitive personal information. As disclosure is a process which begins much earlier than the actual moment of telling, taking the first step of having an HIV test, forms part of the sense of responsibility to others.

Keywords: Communication Privacy Management (CPM) Theory, disclosure of HIV status, HIV/AIDS in Botswana, HIV testing, private information, sexual partner

INTRODUCTION

Disclosure of private information is a complex matter, especially when disclosing one's HIV status, which involves sensitive, potentially life-threatening information and stigma. Disclosure of HIV status to sexual partners is important for managing the HIV/AIDS pandemic. If HIV positive persons should disclose their status, it could lead to safer sex and reduced HIV transmissions.

The Communication Privacy Management (CPM) Theory explains the relationship between disclosure and privacy. This theory proposes five criteria for privacy rules to decide whether to disclose or conceal private information. These criteria (culture, gender, motivations, context and risk benefit) were used to explain the findings of this study (Petronio, 2004:196).

The CPM theory helps to explain decisions regarding sharing sensitive personal private information such as disclosure of HIV status. This theory describes five criteria used as foundations of privacy rules for managing private information (Greene, Derlega, Yep & Petronio, 2003:20). These criteria include cultural aspects, personal motivations, gender, situational context and individual risk assessments under the risk-benefit criterion. The CPM theory also argues that the uniqueness of the recipient of private information is an important factor, influencing whether disclosure will occur or not.

During the past ten years, studies (Simoni & Pantalone, 2004; Norman, Chopra & Kadiyala, 2005) addressed disclosure of HIV status to sexual partners. However, no recent qualitative study investigating this phenomenon in Botswana could be identified. According to Simoni and Pantalone (2004:109), many public health officials have shifted their HIV prevention methods from targeting populations at risk of HIV infection, to those infected with HIV. In some resource-limited settings, HIV status disclosure is a pre-requisite for enrolment into national HIV programmes. In Botswana, the National Aids Coordinating Agency (NACA) operates a "buddy system" whereby each patient is encouraged to form a special bond with someone close, to enhance adherence to HIV treatment. The patients need to disclose their HIV status to the buddy, who could be the patient's partner (Africa Recovery, 2002:4).

According to Zuyderduin and Melville (2000:3), the concept of shared confidentiality was introduced as part of the law in Botswana in 1999 through statutory instrument number 77 of 1999. Through this instrument, the Botswana Medical Council (Professional Conduct Regulations of 1988 as amended in 1999) inserted a new sub-regulation which provides that "a person taking care of, living with or otherwise coming into regular close contact with the patient shall be informed (by medical professionals) of such a patient's

medical condition where the said patient is suffering from a communicable disease or has an infection which may be passed to such a person, if appropriate precautions are not taken". This includes an HIV infected person's sexual partner.

The first HIV positive case in Botswana was diagnosed in 1985. Twenty years later Botswana had the second highest HIV prevalence rate in the world (WHO, 2005:1). New cases of HIV infection are still high as estimated by the Botswana Aids Impact Survey (BAIS III, 2008:3).

Definitions of key concepts

Disclosure describes voluntary and partial disclosure whereby the HIV infected person voluntarily reveals his/her HIV status to his/her sexual partner. Partial disclosure occurs when the person only tells certain people about his/her positive HIV status.

Sexual partner (also referred to as partner) is a person with whom there is engagement in sexual acts, including voluntary sexual intercourse within or outside a committed relationship.

PROBLEM STATEMENT

In Botswana, a developing country with limited resources, where more than 10 000 new cases of HIV infection are reported annually (BAIS, 2008:3), urgent public health interventions are required. The disclosure of a person's HIV positive status has been adopted as a public health strategy to reduce HIV transmission. Consequently, it became critical to understand the factors promoting or discouraging disclosure, for this strategy to impact on reducing HIV transmission rates in Botswana.

PURPOSE OF THE STUDY

The purpose of this study was to explore and describe the positive and negative factors influencing disclosure of persons' HIV positive status to their sexual partners in Botswana in order to recommend ways in which HIV positive persons can be assisted throughout this process.

RESEARCH DESIGN AND METHODOLOGY

A qualitative design was used to explore and describe the factors influencing HIV positive persons' disclosure to their sexual partners in Botswana in order to assist these persons throughout the process of disclosure.

Population and sample

The population comprised HIV positive persons attending a private medical clinic in Gaborone, serving unemployed people, people in low-paid jobs as well as private patients who can afford private healthcare services.

A non-probability purposive sampling approach was used to gather rich data (Wilmot, 2007:2). To be included in this study the participants had to be males or females aged 18-39; regularly utilising the participating HIV clinic for treatment and care, in or having been in a relationship with at least one sexual partner to whom they had disclosed their HIV status. The sample size of nine was determined by data saturation.

Data collection

In-depth, audio-taped interviews were conducted and complemented by field notes. The interviewer was the primary data collection instrument. Written informed consent was obtained prior to conducting each interview.

Data collection began with a *grand tour* question to ensure openness and freedom to talk about experiences. Probing questions were asked (where necessary) to enhance the richness of the responses. The study's purpose served as a guideline to explore relevant focussed information.

Field notes were compiled soon after each in-depth interview to capture and describe the non-verbal cues observed during the interview.

Data analysis

The analysis of data began while still in the field through the emergence of ideas for making sense of the data (De Vos, Strydom, Fouche & Delpont, 2005:336). The process was also guided by the study's purpose and the data analysis steps of Lacey and Luff (2007:3-4). These steps included: familiarisation with the data, transcribing and organising data, coding data (open coding, conceptual coding, categorising data, identifying themes), and literature control.

Trustworthiness

Polit and Beck's (2008:540) five criteria for developing trustworthiness of qualitative research (based on Lincoln and Guba's 1985 framework) were used, namely credibility, dependability, confirmability, transferability and authenticity.

Credibility was enhanced through establishing prolonged engagement with the participants and by carrying out member checks through reflecting statements to participants and requesting clarifications where necessary, to enhance comprehension of specific statements' meaning.

Dependability was assured by collecting, recording, transcribing and translating information as accurately as possible and by providing a literature control, where appropriate.

According to Polit and Beck (2008:539), confirmability establishes that the information provided, and the interpretations of that information, are not figments of the interviewer's imagination. To enhance objectivity to external readers, the interviewer's views, perceptions and assumptions were acknowledged and included in a reflective diary. The interviewer also bracketed her perceptions to reduce the potential influence of prior experiences or perceptions regarding the disclosure of persons' HIV positive status.

Transferability refers to generalisability of research findings to other settings or groups (Polit & Beck, 2008:539). This was achieved through triangulation by using in-depth interviews and field notes, two coders, a reflective diary and a literature control.

Authenticity refers to the extent to which researchers fairly and faithfully show a range of realities by conveying the feeling and tone of the participants' lives as they are lived (Polit & Beck, 2008:540). To demonstrate this criterion, some direct quotations from participants' interviews have been included, accompanied by background information such as time of the day, facial expressions and other relevant non-verbal cues.

ETHICAL CONSIDERATIONS

Ethical approval was obtained from all relevant authorities. Ethical considerations included the following steps: informed consent, voluntary participation, maintaining anonymity and confidentiality of the participants, and maintaining autonomy, beneficence, non-maleficence and justice (South Africa, 2000: Para 1.3.1)

RESULTS

The participants' ages ranged from 26 to 39. There were seven females and two males. Four participants were unmarried but were co-habiting. There were no divorcees or widowers. Only one participant was unemployed. No participant was in a same-sex relationship.

Guided by the steps identified by Lacey and Luff (2007:7) eight themes, with categories and sub-categories, emerged from the collected narrated data. The themes and categories are presented in table 1.

Table 1: Summary of themes, categories and sub-categories

THEMES	CATEGORIES	SUB-CATEGORIES
1. Reasons for HIV testing	Health	Own illness; partner's illness
	Family planning	Pregnancy; more children; partner's needs
	Public health campaign	Media Cultural sensitivity
2. Pre-disclosure deliberations	Negative thoughts	Fear and anxiety about stigma and cultural marginalisation
	Positive thoughts	Self-counselling; lifestyle changes
	Indifference	Resignation to fate; no concerns
3. Process of disclosure	Pre-disclosure clues	HIV discussions; HIV test results; ill health, accessibility of media messages, contextual in terms of appropriateness and availability of communication means
	Time scale	Immediately; days; never
	Mode of communication	Phone Face-to-face
4. HIV status disclosure: reasons	Others-focused	Responsibility; living together; HIV perceptions; relationship; safe sex
5. Reasons against disclosing HIV status	Discloser's perceptions	Self-respect; fear; readiness
	Partner perceptions	Rejection; end of relationship; blame; lack of support; worrying others; past experiences; non-acceptance
	Other perceptions	Stigma; views on HIV
6. Initial reaction to disclosure	Self	Deflation; disappointment and sadness; emotional trauma; relief
	Partner	Acceptance/support; anger; lack of support; disbelief/denial

7. Consequences of disclosure	Positive effects	Emotional support; mental well-being; condom use; financial support; relationship strengthening
	Negative effects	Risk of psychological abuse; physical abuse; relationship breakdown; rejection, cultural insensitivity
Participants' recommendations	Supportive measures	Professional counselling; simultaneous couples' HIV testing; third party mediation
	Punitive measures	Legislation; withholding of services

Theme 1: Reasons for HIV testing

The main reasons for HIV testing, as identified by the participants, were related to health issues:

"I had been having recurring illnesses ... I needed to know what was causing it";

"My husband was very keen to have a second child, I proposed that we have the test first". "I became pregnant in 1997 ... asked if I would agree to have an HIV test";

Some participants' decisions were partially influenced by public health messages, as indicated by the following statement:

"Yes, they keep telling us about this illness and suggesting people should know their status".

Theme 2: Pre-disclosure deliberations

Participants described their thoughts, concerns, debates and deliberations after learning about their HIV positive status and before telling their partners. Negative, positive and indifferent thoughts were described. Negative thoughts included fear, anxiety and worries about their partners' reactions and cultural implications. Issues such as whether they believed in the traditional explanations of HIV infection and treatments; or in the modern explanation and use of anti-retroviral drugs (ARVs).

"I was scared ... as soon as I tell him he might leave me ... I was also unsure as to what he would do".

Positive thoughts included self counselling, acceptance and a commitment to positive lifestyle changes:

"... decided to counsel myself and to prepare myself in case my results came back positive". I also decided that if I am negative, I will review my lifestyle accordingly".

Some participants were indifferent and reported:

“I had no concerns at all”.

“I didn’t even think about what I would do or what effect it would have on me if I was told I was positive”.

Theme 3: Process of disclosure

Participants highlighted how they told their partners about their HIV positive status. Pre-disclosure clues involved partner reaction assessment in preparation for the big reveal as exemplified by one participant:

“You listen to himyes ...when you have general conversation about the public health messages about the disease”.

Graded introduction to the subject was also reported:

“What I did was to introduce the subject gradually. First I... told them I had tablets that I needed to take in the mornings and evenings every day...and asked them to remind me if I forgot a dose. So they got used to the idea that I take medication first. Later on I told them what the medication was for”.

Partner priming involved keeping the partner updated with the changing events surrounding the discloser’s HIV related activities such as going for HIV counselling and testing (HCT), and then informing the partner that they were going to get the results about which they would need to talk. Disclosure mostly occurred on the same day or within a few days of learning about the HIV positive status (personally or by phone or by e-mail):

“... immediately after I came back from ‘the clinic’ ...”;

“I told her my results the next day”.

Theme 4: Reasons for participants’ disclosure of their HIV positive status

Categories describing reasons why disclosure occurred were ‘others-focussed’ and ‘self-focussed’. Others-focussed reasons were described as: a need to protect others from HIV transmission, a sense of responsibility, living in the same household, non-disclosure is selfish. One participant described this aptly:

“It will be a terrible thing to ... sleep with your partner without a condom especially if he is used to sleeping with you without one ... when you know your status and you

haven't told him. You could pass the virus on to him, which ... will be a bad thing to do".

Other participants disclosed because they believed that if their partners knew, they would be more inclined to use condoms. Disclosing to protect others, due to a sense of responsibility, was an important reason for partner disclosure.

Self-focussed reasons centred on what the participants hoped to gain by telling their partners. Gaining acceptance and emotional support from their partners was an important motivator to disclose. Other reasons included hope for support to deal with the physical aspects of the illness, including side-effects from the ARVs or financial support:

"I told him unless you give me money to go seek treatment, I won't leave you alone all night".

Theme 5: Reasons against disclosure of participants' HIV positive status

The infected persons' beliefs about HIV/AIDS, influenced their disclosure behaviour. One participant described low self-esteem, almost a sense of self-loathing:

"I felt like a prostitute".

Participants reported that there had to be a level of readiness before they decided to disclose. Partners' perceptions of how the HIV positive person thought his/her partner would react to the disclosure were key influences in the disclosing process. Negative perceptions, making disclosure difficult included rejection, non-acceptance, blame, lack of support from partner and past negative experiences.

Concerns for others related to disclosure to family members rather than to partners:

"This means if he had not told me first, I was going to keep it quiet ... I even thought that he would end the relationship".

Negative public perceptions and HIV stigma also made disclosing difficult:

"One of my brothers is a doctor, I think he would be discriminated against ... I don't want my relatives to be stigmatised".

Theme 6: Initial reactions to disclosure of participants' HIV positive status

Both the HIV infected participants and their partners had positive and negative reactions to the initial disclosures. Feelings about the self varied from relief to sadness, disappointment, deflation and emotional trauma. One participant attempted suicide:

"I was sorry I didn't die, I really wanted to die that day because I was in so much pain".

However, one participant said: *"Then I started to relax"*.

Another participant reported feeling emotionally weaker since the disclosure:

"I seem to lose my patience easily these days ... I realised in the end that my experiences with that ... did affect me".

Some partners reportedly reacted to the disclosure with acceptance and supportiveness but also with denial and a lack of support:

"He said don't worry, we are always told that this virus attacks everyone".

"He went mad ..."

"She didn't want to be in the relationship anymore ..."

Theme 7: Consequences of disclosure of participants' HIV positive status

Weighing the benefits and risks of disclosing, which consists mainly of perceived positive and negative outcomes following disclosure of private information was also found to have influenced disclosure. Positive effects included emotional and financial support from both partners and families: increased condom use, positive impact on some relationships, partners' and relatives' enhanced support and emotional well-being:

"He still treats me very well".

"We have agreed to use condoms. He has no problems with that".

"Right now we live together in harmony. We don't have fights about his previous lifestyle of running around".

Negative effects included psychological trauma, relationship breakdown, blame and rejection:

"These things made my life miserable".

“In the meantime, my partner not only refused to do the test but also refused to use condoms. It became such an abusive relationship”.

Theme 8: Participants’ recommendations

Most participants recommended partner disclosure as the right thing to do regardless of their own experiences. Supportive measures which could enhance disclosure included simultaneous couple HIV testing, professional counselling and third party mediation:

“I think they should include it as part of ongoing counselling. People should be advised on what to do in case they are positive and how to approach the issue of disclosing to partners”.

Some participants suggested punitive measures against those intentionally spreading HIV by not disclosing their status such as legal means and withdrawal of access to government ARV services.

“There is nothing the government can do to help ... serious measures have to be taken against them”.

DISCUSSION

Reasons why people undergo HIV testing can influence the disclosure of their HIV positive status to their sex partners. The results of this study, regarding reasons for testing, were similar to those of other studies. Steen, Seipone, De la Hoz Gomez, Anderson, Kejelepula and Moffat (2007:486) reported that the main reasons why respondents underwent routine HIV testing were due to patients’ wishes (50.1%) and pregnancy (24.7%).

Weiser, Heisler, Leiter, Percy-de Korte, Tlou, DeMonner, Phaladze, Bangsbeng and Lacopino (2006:1017) conducted a cross sectional study on 1268 adults in Botswana, assessing their knowledge of and attitudes towards routine HIV testing. They found that factors associated with HIV testing included older age, female gender, higher education, higher income, self reported excellent health status, access to good health care, access to HIV testing and respect from healthcare professionals.

Factors influencing individuals to undergo HCT might influence the disclosure of their HIV status. Fear of having to deal with issues of disclosure was not directly reported as a barrier to HIV testing in the current study. However, Greeff, Phetlhu, Makoane, Dlamini, Holzemer, Naidoo, Kohi, Uys and Chirwa (2008:312) observed that HIV positive persons have concerns about HIV-related stigma, making them less willing to use HCT services.

Findings from the study revealed that HIV positive people think about disclosure and take it very seriously such that if they would not have disclosed, it is because of several layers of deliberations, experiences and not purely because of selfishness or irresponsibility. Rutledge (2007:1044) described disclosure as a process involving timing, staging and enacting disclosure. In the current study, one participant initially introduced the issue of taking pills and asking the children to remind her daily. When they were comfortable with the knowledge and arrangement, she then told her eldest daughter, and later the younger children, about her HIV positive status.

Participants disclosed their HIV positive status to their partners because they had a sense of responsibility, lived in the same household, expected personal gains such as emotional and financial support, and not to keep secrets. The findings from the current study correlate with those of Chandra, Deepthivarma and Manjule (2003:207).

Based on the findings of this study, the uniqueness of the recipient becomes the major overriding factor in deciding whether or not to tell, when outcomes of disclosure are perceived rather than experienced. A holistic perspective is necessary for understanding issues involved in an individual's disclosure of private information.

CONCLUSION

Persons have to deal with the issue of disclosing their HIV positive status when they decide to use HCT services. Disclosure therefore begins much earlier than the actual moment of telling, starting before the HIV test and probably continuing beyond the moment of disclosure. Based on the findings of the study, the most important factors influencing disclosure are related to 'others-focus' and 'self-focus' and include the sense of responsibility, living in the same household as the partners, needs for emotional support, not feeling comfortable with keeping secrets and financial needs.

The self-focussed versus others-focussed reasons are the key to understanding and appreciating the dialectical tension that exists between maintaining privacy and disclosure as described by the CPM theory. The uniqueness of the recipient of information about the status of the HIV positive person becomes a major overriding factor in the process of disclosure. The rules of privacy management are therefore influenced by the outcomes which may impact on the HIV positive person when making decisions on whether to disclose or not. The CPM theory clarifies and helps to explain decisions regarding sharing sensitive personal private information such as disclosure in terms of culture, motivators, gender, context and risk benefit.

RECOMMENDATIONS

To enhance disclosure the recommendations are based on both the main components of the content and the process of disclosure as well as the criteria described under the CPM theory.

The recommendations take cognisance of ‘self-focus’ and ‘other-focus’ factors and are relevant to practice and health education as well as for further research. As disclosure entails the management of private information the recommendations are presented within the five criteria of the CPM theory.

Culture: Public health messages should tailor their content towards cultural sensitivities prevailing in target communities. The language used should be such that it conveys the appropriate message without being offensive and taking cognisance of cultural practices and taboos.

Motivators: The study has demonstrated the personal nature of factors influencing disclosure of HIV status to partners. Efforts to encourage disclosure should attempt to personalise disclosure-related messages set by public health specialists. This could be achieved to some degree by involving the patients’ doctors who conduct one to one consultations with HIV infected persons at medication reviews. Counselling could be positively re-enforced by health care professionals’ attitudes and the positive nature of health education.

Gender: Counsellors should be knowledgeable regarding the effect of gender and sexuality on disclosure of HIV status and must therefore be gender sensitive to deliver relevant counselling services.

Context: Pre-HCT services should aim to address issues related to disclosure of one’s positive HIV status. Initial introduction of the subject could be done during the HCT. Further discussions to address concerns relating to disclosure of HIV status could then be continued during subsequent sessions with those who are HIV positive. TV messages might not reach those in the villages even though they would easily reach those living in cities. Using text messaging to distribute HIV prevention messages might be better received by the younger generation compared to the older generation

Risk-benefit: HIV positive individuals should be empowered to analyse their own individual situations to know when it is right to tell and when it is not. In this way negative experiences, following disclosure, could be minimised

Recommendations for practice and health education

Where appropriate, sexual partners should be offered simultaneous HIV testing, in a sensitive and diplomatic manner. Partners will need counselling before and after testing, especially in cases of sero-discordance.

A statistically validated screening tool which captures factors identified as influencing disclosure of HIV positive status could be produced and administered as part of pre-HIV testing to identify those at risk of negative outcomes following disclosure

The importance of contextual and relevant health education after receiving positive HIV results cannot be over-emphasised.

There is a need for cultural sensitive and personalised local support systems for those dealing with the consequences of disclosure. Such systems could include a confidential help-line accessible 24 hours per day, and local support groups comprising those who have experienced negative HIV disclosure outcomes.

Recommendations for further research

It might be tempting to advise HIV positive persons, afraid to disclose, that disclosure could contribute to reducing HIV transmission through adopting safe sex practices, but caution needs to be exercised as the current evidence remains inconclusive. Further research is recommended in this area, through a quantitative study to investigate the rates of condom use following disclosure of one's HIV positive status to partners among sexually active HIV infected persons in Botswana.

Some participants suggested punitive measures to be taken against those who do not disclose to partners. Further studies should assess the understanding of HIV positive persons of the legal implications of non-disclosure in Botswana. These research findings could shed light on such punitive measures' acceptability to the HIV infected persons and what effect these measures might have on disclosure rates.

LIMITATIONS

Participants were aware that the interviewer was a healthcare professional. This might have influenced the information captured, depending on whether participants thought it was deemed appropriate or not for them to share some of the information. The interviewer tried to reduce this by allowing participants to talk freely and by not making any judgemental statements. Emphasis was placed on collective benefit rather individual gain from the study and participants were assured that the narratives provided were not corroborated with others' stories.

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