Stigma and HIV disclosure in the Cape Metropolitan area, South Africa

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Disclosure rates of HIV-positive status remain low and are considered to be related to stigmatisation. Determining the factors that influence a person’s decision to disclose a positive status is essential to understanding the process of and ways to improve disclosure rates. This study investigated the factors that influence the disclosure of a person’s HIV-positive status and focused on socio-demographic factors, stigma and discrimination, religion, culture, fear of abandonment and rejection as well as knowledge of the disease that may all influence disclosure rates. A facility based descriptive cross-sectional research design with a quantitative approach was applied using convenience sampling. The sample comprised 150 individuals which was 12.5% of the study population. A self-administered questionnaire comprising mainly closed-ended questions, with a limited number of open ended questions was designed, tested and utilised. Statistical associations were determined between the demographic factors and responses to the questions. The open ended questions were analysed thematically by means of content analysis to extract meaning. The results revealed that fear of stigmatisation, especially among the male participants, was a major reason for delayed or non-disclosure. The results of the total study sample also showed that the level of education influenced the fear of stigmatisation; those with secondary school level education were most afraid of this (29%). There was a statistically significant association between fear of blame or discrimination and disclosure to the sexual partner. This fear was most often cited by the participants who had never married (19%). The participants who feared blame or discrimination the most reported having no income (23%). The findings of this study indicate that numerous factors influence HIV disclosure. Stigma of individuals who are HIV-positive remains a barrier to disclosure as well as fear of blame and discrimination. Recommendations were made to facilitate and increase disclosure rates. This should include community based support groups and advocating partners to attend voluntary counselling and testing together to minimise the fear of blame.

Keywords: counselling, discrimination, people living with HIV/AIDS, prevention

Introduction

The concept of disclosure and the fundamental attributes of HIV disclosure are complex and not fully understood. This makes it difficult to effectively counsel an individual through the disclosure process. The attributes of HIV disclosure include experience, communication, timing, the contextual environment, protecting someone and the relational status (Türmen 2003, Simbayi et al. 2007, Eustace and Ilagan 2010). The principal investigator’s clinical practice identified that most HIV positive clients who were treated for minor ailments or injuries failed to disclose their HIV positive status to their sexual partner.

HIV disclosure is the process of making known to others the seropositive or seronegative status with specific regard to HIV infection (Zunniga 2010). The prevention of new HIV infections through disclosure has been scientifically reduced the incidence of HIV (Pinkerton and Galletly 2007, Simbayi et al. 2007, Wong et al. 2009). Non-disclosure may also be related to the internalisation of stigma due to the social belief that the individual is responsible for the infection and therefore has an imperfect social identity. This study found that the men commonly expressed feeling dirty, guilty and ashamed and that it was their own fault. Multiple factors are associated with disclosure, and disclosure rates remain low (Simbayi et al. 2007, Deribe et al. 2008, Wong et al. 2009).

Sexual partners who fail to disclose their HIV status are less likely to change sexual behaviour and practise safer sex than individuals who have disclosed their status (Pinkerton and Galletly 2007). Consequently, the effect of not disclosing one’s HIV status to sexual partners may have implications in the transmission of the virus. Studies on HIV disclosure completed in South Africa have predominantly focused on male to male sexual relationships. Gaskins (2006) reported that disclosure to the sexual partner by men who have sex with men was 67% to 88%. This rate decreased with casual partners and also if the individual had more than one sexual partner. Deribe et al. (2007) noted that the factors which influence disclosure are the awareness of the partner’s status, living in the same home and the phase of the disease. Simbayi et al. (2007) conducted a study in Cape Town, South Africa, and determined that 42% of participants indicated that they had not disclosed their status to their sexual partners. The higher rate of non-disclosure was among married men who
had more than one sexual partner. Most research suggests that the barriers to disclosure include fear of abandonment, loss of financial support, discrimination, violence and fear of being accused of infidelity (Gaskins 2006, Deribe et al. 2008).

This study focussed on determining the socio-demographic factors influencing HIV disclosure and was conducted in the Cape Metropolitan region of Cape Town, South Africa. The aim of this study was to investigate the factors which influence the disclosure of a person’s HIV-positive status to enhance the understanding of the factors that influence the rate of transmission of HIV.

Disclosure is an important prevention goal, emphasised by the World Health Organization (WHO) protocols for HIV testing and counselling (Norman et al. 2007). This study provided evidence related to the factors that influence a person’s decision to disclose his/her HIV-positive status to others, particularly the sexual partner within a context where HIV is considered a serious healthcare concern. The information gained may strengthen healthcare professionals’ understanding of the complex elements of disclosure.

Methodology

A quantitative approach applying a facility based descriptive cross-sectional design was used to determine the factors influencing disclosure of HIV status. The target population in this study included all the HIV infected clients who attended a community health clinic for HIV management in the Cape Metropolitan area. A total of 1 200 HIV infected clients were receiving treatment at this particular clinic at the time of data collection. A convenience sampling method was applied that included the first 150 clients who voluntarily agreed to participate and met the eligibility criteria for the study — being HIV-positive and 18 years or older. A sample size of 100 clients achieves 9% precision when constructing a 95% confidence interval for the true population proportion. Thus, the sample size of ($n = 150/12.5\%$) was adequate to survey the disclosure parameters within an acceptable degree of accuracy.

A self-administered questionnaire was developed using dichotomous and categorical questions. The questionnaire consisted mostly of closed-ended questions with three open ended questions. This allowed participants to comment on what helped them disclose their status, their understanding of the diagnosis and recommendations for helping people disclose the positive status.

The questionnaire was divided into two sections. These were a demographic information section that focussed on aspects such as gender, age, race, relationship status, monthly income, religion and education level. The influence of these aspects was related to disclosure rates. The second section focussed on factors that influence disclosure, for example, to whom and when disclosure takes place and the factors preventing disclosure. These included the fear of stigma and discrimination, blame, acceptance in their culture, fear of abandonment and rejection as well as knowledge of the disease.

Several questions investigated to whom the participant first disclosed their HIV-positive status and how long it took from the time of diagnosis to disclosure. Participants were also asked to state whether they were aware of their sexual partner’s HIV status. Questions relating to disclosure to the sexual partner and other network partners were asked separately.

The questionnaire was based on an extensive review of the literature, discussions with experts in the field and with an expert in nursing research methodology. The face and content validity was confirmed by five HIV/AIDS experts in the field of nursing. The questionnaire was also structured to obtain the required information in a way that is easy to comprehend and not complicated to complete. The reliability was determined by conducting a pilot study to ensure that the intended data were captured and that the questions were relevant. The results of the pilot study were reviewed by the statistician.

The instrument was piloted on 10% of the number of participants who attend the HIV division at the CHC to ensure that the intended data were captured and that the questions were relevant and relatively easy to understand. Minimal changes were made to the questionnaire. Three questions were removed as they were found to have answers that were repeated in other questions and did not affect any other aspect of the intended research. The final version of the questionnaire obtained the feasibility go-ahead from the statistician supporting the project.

Ethical approval for the study was provided by the Health Research Ethics Committee of the Faculty of Health Sciences, Stellenbosch University. Permission for the study was received from the Health Division of the City of Cape Town. Written informed consent was obtained from each participant following the distribution of a participant information leaflet to each participant. The consent form was available in English, Afrikaans and isiXhosa. Once the consent form was read and signed, the participant was guided through all the questions.

All clients attending the HIV clinic were included in an information session and a group discussion, while they were waiting to be seen by the clinical nurse practitioner or doctor. Due to the sensitivity of disclosing a person’s HIV status, a counselling service was provided for participants who became emotionally affected by the data collection process or who opted for help in the process of disclosure.

The data were collected by the researcher and one trained field worker. The researcher trained a nurse assistant who worked in the HIV division as a field worker. She was familiarised with the study, the research process, ethical considerations and questionnaire. As the field worker was fluent in English, Afrikaans and isiXhosa, she was able to translate information as required and to assist participants complete the questionnaire when necessary.

During data collection and analysis anonymity and confidentiality were protected by coding each questionnaire with an identifying number. The participants were individually assisted to complete the questionnaire by the researcher or field worker to ensure uniformity. They were allowed to take as long as they needed to answer; this was approximately 20 minutes.
Data analysis

Quantitative data were captured on a Excel spreadsheet and the software package STATISTICA version 9 was used to analyse the data. Distributions of variables were presented using histograms and frequency tables. Statistical associations were determined between the various variables using the chi-square, Spearman and t-tests. The qualitative data obtained from the open ended questions were categorised, grouped into trends and analysed thematically.

Findings

The mean age of the participants was 36.02 years; most of them were between 26 and 35 years old and were Christian (Table 1). The sample was made up of 71% females and 94% of the participants classified themselves as Black. The area where the research was done is generally considered to be cosmopolitan and as such a limited diversified sample in terms of race was considered interesting. (Table 1). Close to half the participants (45%), were never married and 43% were unemployed and not receiving any income (Table 1). There was only one female who reported that she had never disclosed her HIV-positive status to anyone. This excluded disclosure to healthcare professionals, who most often do the test and are aware of the result. There was no significance noted and disclosure rates were 99%.

Factors influencing disclosure

A statistically significant association was found between age and disclosure, with the mean age for disclosure at 36.02 years and non-disclosure at 19 years. Most participants were between the ages of 26 and 35 years (Figure 1). The younger the person was at time of diagnosis, the lower the disclosure rate, and vice versa. Women disclosed to family members first (37%) and then to their spouse/life partner (27%). Men disclosed most often to their spouse/life partner (17%) as shown in Figure 2. Only 1% disclosed to work colleagues or religious leaders.

The relational status of the participants and to whom they disclosed their status was statistically significant. Married individuals most often disclosed their status to their spouse/life partner (63%) and those who had never married most often to their family (55%). Disclosure to casual sexual partners was the same for married and unmarried participants (4%). Results also indicated that income influenced disclosure rates. The participants who feared blame or discrimination the most reported having no income (43%), as shown in Table 1. The level of education influenced the fear of stigmatisation where individuals with a secondary education level fearing disclosure the most.

If one reflects on the awareness of the partner’s HIV status, 57% of the participants were unaware of their sexual partner’s status. A statistically significant association was found between the female’s and male’s awareness of the sexual partner’s HIV status. The number of females who

Table 1: Demographic characteristics of study population

<table>
<thead>
<tr>
<th>Gender</th>
<th>Number of participants (n = 150)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>106</td>
</tr>
<tr>
<td>Male</td>
<td>44</td>
</tr>
<tr>
<td>Relationship status</td>
<td></td>
</tr>
<tr>
<td>Never married</td>
<td>67</td>
</tr>
<tr>
<td>Married</td>
<td>47</td>
</tr>
<tr>
<td>Divorced</td>
<td>14</td>
</tr>
<tr>
<td>Widow/Widower</td>
<td>13</td>
</tr>
<tr>
<td>Life partner</td>
<td>1</td>
</tr>
<tr>
<td>Traditional</td>
<td>8</td>
</tr>
<tr>
<td>Monthly income</td>
<td></td>
</tr>
<tr>
<td>Nil</td>
<td>64</td>
</tr>
<tr>
<td>Social grant</td>
<td>14</td>
</tr>
<tr>
<td>Less than R2000</td>
<td>34</td>
</tr>
<tr>
<td>Between R2001 and R4000</td>
<td>30</td>
</tr>
<tr>
<td>More than R4001</td>
<td></td>
</tr>
<tr>
<td>Educational level</td>
<td></td>
</tr>
<tr>
<td>No education</td>
<td>3</td>
</tr>
<tr>
<td>Grade 1–7</td>
<td>27</td>
</tr>
<tr>
<td>Grade 8–12</td>
<td>109</td>
</tr>
<tr>
<td>Tertiary education</td>
<td>11</td>
</tr>
</tbody>
</table>

Figure 1: Ages of participants in the study

Figure 2: First person to whom participant disclosed HIV status
were unaware of their sexual partner’s status was 33%. The number of males who were unaware of their sexual partner’s status was significantly lower with only 10% of this group being aware (see Table 2). A significant statistical association between awareness of the sexual partner’s HIV status and the relevant relationship status was found. Participants who were never married (22%) had the highest rate of not being aware of their partner’s status. Participants who were married had the highest rates of awareness of their partner’s status (24%).

Fear of stigmatisation was identified as an important factor that influenced HIV disclosure to others, especially among the male participants, thus revealing that this was the major reason for delayed or non-disclosure. Male participants feared stigmatisation more than the female participants; this result was statistically significant (Table 2). The results indicated that the reasons for delayed or non-disclosure differed between the two groups of sexual partner and others, namely friend, family, work colleagues and religious leaders.

Most of the participants disclose either to their main partner (44%) or to family (45%), although 14% delay the disclosure and have sexual relations with the individual before admitting to being HIV-positive (Figure 3). There was a statistically significant association between fear of blame or discrimination and disclosure to the sexual partner. This fear was most often cited by the participants who had never married. It was meaningful that all the participants indicated that they believed that HIV was mostly accepted in their culture as a part of life, and that it did not affect their ability to disclose their HIV-positive status. However, a contradiction became apparent in that there was an expressed fear of blame, rejection and stigmatisation but found it difficult to disclose in a community that accepted HIV as a part of life.

Participants were also requested to indicate their understanding of their HIV diagnosis. Most (40%) stated that HIV was incurable, but that medication could control the virus. The overall theme that emerged was that individuals should practise safe sex by using condoms and having one partner, lead healthy life styles such as exercise, no smoking or alcohol and to exercise regularly.

**Discussion**

**Socio-demographic factors**

The findings from this study suggest several socio-demographic factors that influence disclosure of HIV status. Females tend to disclose to family members first and then to their spouse/life partner. This delayed disclosure to the sexual partner of the females may lead to an increase in the transmission of HIV due to continued unsafe sexual practice and the incapacity to make informed decisions with regards to sexual behaviour due to ignorance of the partner’s HIV status. Males disclosed most often to their spouse/life partner. These results were supported by those of another study conducted in Ethiopia which found that males disclose their status to partners more often than females do (Deribe et al. 2007).

Furthermore, women are more likely to acquire HIV infections due to biological factors, with male to female transmission of HIV two to four times higher than that of female to male (Türmen 2003). Women with sexually transmitted diseases are often asymptomatic; this may result in delayed treatment and increasing the transmission of HIV tenfold. Women also lack the power and financial independence to negotiate safe sex and insist on condom use (Greig et al. 2008).

In reflecting on the variable of age, the study found that younger people disclosed their status less often than older participants did. However, these results seem to differ from those documented by Medley et al. (2004) who found that older people disclosed their status less often. According to O’Brien et al. (2003) younger women are more likely to disclose to their sexual partner whereas older women are more likely to disclose to a friend.

Another factor that influences disclosure rates is relational status. In this study married individuals most often disclosed to the spouse/life partner (63%) and those who were never married disclosed to their family (55%). A study in Ethiopia by Deribe et al. (2008) also found that most of the participants disclose to their main partner, although 14% delay the disclosure and have sexual relations with the individual before admitting to being HIV-positive. Less than half of those who are HIV-positive tell their casual partner.

In many societies women have a lower social and economic status simply because they are women and, thus are seldom in a position to discuss safe sexual behaviour.

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**Table 2: Factors influencing HIV status disclosure**

<table>
<thead>
<tr>
<th>Variables (n = 150)</th>
<th>Number of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Female</td>
</tr>
<tr>
<td>Disclosure of HIV positive status to sexual partner</td>
<td></td>
</tr>
<tr>
<td>Disclosure</td>
<td>48</td>
</tr>
<tr>
<td>Non-disclosure</td>
<td>57</td>
</tr>
<tr>
<td>Awareness of partner’s HIV status</td>
<td></td>
</tr>
<tr>
<td>Not aware of status</td>
<td>49</td>
</tr>
<tr>
<td>Awareness of status</td>
<td>57</td>
</tr>
<tr>
<td>Fear of stigmatisation</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>46</td>
</tr>
<tr>
<td>No</td>
<td>60</td>
</tr>
</tbody>
</table>

**Figure 3: Time from diagnosis to first disclosure**

- **Same day**: n = 11
- **Days**: n = 9
- **Weeks**: n = 21
- **Months**: n = 8
- **Years**: n = 100
(Türmen 2003). A study conducted in South Africa by Greig et al. (2008: S38) revealed that "poorer women were more likely to have early sexual debut, a non-consensual first sexual encounter and higher rates of physically forced sex or having exchanged sex for money, goods or favours — all significant risk factors for HIV". The researchers also indicated that women who have some financial security are better able to avoid these relationships and their resultant improved power status helped reduce the risk of HIV.

**Stigma and discrimination**

Results indicated that the reasons for delayed or non-disclosure differed when disclosing to the sexual partner and disclosing to others such as a friend, family, work colleagues and religious leaders. The fear of stigmatisation was identified as a factor which influences HIV disclosure to others, especially among the male participants, and as being the major reason for delayed or non-disclosure. Most participants felt that HIV was accepted in their culture. This might be the effect of a relatively poor and superficial formulation of the question that did not define the concept of acceptance. HIV is a socially unacceptable disease and results in the community discriminating against an individual's lifestyle and personal behaviour (Simbayi et al. 2007, Chaudoir et al. 2011, Keikelame et al. 2010).

A study that reflected on the quality of life in the social context, for example, social contact and family support, found that scores relating to quality of life remained low. This was attributed to HIV-positive individuals who were still exposed to stigma and discrimination (Folasire et al. 2012). Therefore stigmatisation is considered a major negative influence on disclosing a socially devalued illness or condition, such as HIV. The level of education influenced the fear of stigmatisation, with participants with a secondary school level fearing stigmatisation the most. In this study, fear was also most often cited by the participants who had never married (19%).

**Religion**

There were no significant findings in this study with regard to religion as most participants (88%) were Christian and this could thus not be meaningfully correlated with the response questions of disclosure. Only one person disclosed to a religious leader and work colleague respectively. This may also relate to the fear of discrimination. In South Africa it is postulated that faith-based organisations may add to discrimination by associating HIV and AIDS with sin (Keikelame et al. 2010).

**Fear of abandonment and rejection**

In this study the participants who feared rejection the most were those who had never married. These participants cited fear of rejection with regards to disclosure to the sexual partners only and not to the other categories of relationships. Caregivers of children with HIV reported not having told the child of their HIV-positive status for fear of them being rejected by society (Maholko and Madiba 2012).

According to WHO (2004), the fear of abandonment among women is most often cited in developing countries. This is directly correlated to the loss of financial support from the partner. Consequently this reluctance to disclose their HIV-positive status may be the result. Another factor which was identified is that participants with no income also feared rejection more than the participants with some level of income. Again, this was specifically disclosed to the sexual partner. An important factor to note is that because more women get tested for HIV the burden of disclosing is often on them — this may increase their risk of discrimination and rejection (Greig et al. 2008).

**Knowledge and understanding of HIV/AIDS**

The highest level of education documented by most participants (73%) was grades 8–12. The health education level of the participants seemed to be incongruent as their knowledge of the disease and its physical effects were limited, with only 14% aware that it destroys one’s immune system and that it could be a life threatening disease. Most participants (65%) did reveal that there was some level of understanding about HIV/AIDS and they realised that it was currently incurable.

Almost half of participants were not aware of their partner’s status (43%). This was most often found among the participants who were not married. These were also the individuals who feared abandonment and rejection, especially from the sexual partner. Only a few participants (25%) stated that it was necessary to practise safe sex by using condoms regularly and to remain faithful. Knowledge of HIV/AIDS was investigated by Türmen (2003) who found that although 90% of the sample had heard about AIDS, only 16% knew enough to be able to safeguard themselves against the disease.

The process of disclosing one’s status is complex. Individuals must therefore understand the importance and implication of disclosing or not disclosing, especially to the sexual partner, to reduce transmission of HIV/AIDS.

**Recommendations**

From the study, it could be deduced that multiple counseling sessions offered to clients once they have disclosed their status would be important to provide ongoing support and encouragement. Local authorities and clinical nurse practitioners in the healthcare clinics could take a more active and specific role in creating opportunities in this regard. Support services are currently focused on educational counselling rather than being based on a therapeutic model (Haffejee et al. 2010). The provision and encouragement of combined partner counselling may reduce the barriers to disclosure and increase the awareness of the partner’s status, which remains unacceptably low.

Fear of abandonment and fear of discrimination and isolation from the family and community is cited as an important barrier to disclosure of HIV status, both in developed and developing worlds. The findings from the open ended questions also emphasised the importance of assuring that individuals have access to support groups. Support groups seem to provide much needed support and coping skills to accept their HIV-positive status and live normal lives. These support groups also encourage and advise others on aspects such as disclosure, and the
positive reaction that they received as well as information about the medication. Many participants stated that attending these groups reduced their anxiety and stress levels.

Healthcare programmes in this niche area need to be community based in an attempt to reduce the stigmatisation of individuals with HIV and increase their access to social support systems and healthcare facilities. Programmes aimed at empowering women to change gender norms and access some form of income and financial security, which would allow increased independence and reduce the fear of abandonment when disclosing, should be introduced.

We recommend offering culturally appropriate counselling to the intended populations. Involving men in voluntary counselling and testing will reduce women’s burden of disclosing and promote safer sexual behaviour practices, as this is often the male’s decision. The lifestyle and personal behaviour of individuals should be taken into account as well as the physical and psychosocial environment. Knowledge based programmes on HIV/AIDS should be offered to the community, in churches, the work environment and at healthcare facilities. Advocating health promotion is considered critical, as it creates awareness within the community, helping to change important attitudes and misconceptions.

Limitations

This study was limited to one CHC in the Cape Metropolitan area and it was difficult to generalise based on the small sample size. Convenience sampling was used and this may not adequately represent the entire clinic population. Unfortunately, the race distribution was limited; participants were mostly black. Therefore no correlations could be made in terms of the different races usually attending such a clinic. This reality could, however, be attributed to the high incidence of HIV/AIDS positive Africans in comparison to other groups in the Western Cape province (Statistics South Africa 2010). The questionnaire was completed with the assistance of the researcher or field worker and this may have given rise to inaccurate results with the participant trying to provide the ‘correct answer’ in the presence of the healthcare workers.

Conclusion

The study identified numerous factors that influence HIV status disclosure. Disclosure is a multifaceted process and more than one or a combination of factors may influence disclosure. The community and society in which such healthcare clients live and work may directly affect the ability of an individual to remain healthy or to cope with an illness such as HIV. Understanding why, why not, when and how individuals will disclose their HIV status are considered important to assist health professionals to better identify and support such individuals over time and in a range of health contexts. These contexts include multiple counselling sessions and community based programmes with support groups.

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References


