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Disclosure and Non-Disclosure of HIV Positive Status to Partners among Pregnant Women at a Regional Hospital in Swaziland

Article by Roger Maziya[1], Cynthia Z. Vilakati[2]
[1]*MSN Texila American University, Swaziland*
Email: [1]millamaziya@yahoo.com, [2]cythiav@uniswa.sz

Abstract

Individuals diagnosed with HIV often have difficulty disclosing their status to others, yet hiding the diagnosis can have serious implications. Disclosure of HIV status involves a process of decision-making, based upon numerous factors. This study was done to explore the reasons why some women disclose and some do not disclose their HIV status.

The study was conducted in a regional hospital in Manzini. The researcher employed the qualitative descriptive phenomenological methodology. Convenience and purposive sampling were utilized, and the data collection methods were in-depth Interviewing methods. A total of 15 pregnant women attending antenatal care were interviewed.

Most prominent reasons for disclosure of the HIV status by pregnant women attended to for the PMTCT program were that of the need to practice safer sex. Some felt the need to disclose because it would make their sexual partners to protect the unborn babies and to reduce the chances of re-infection. Most women who disclosed stated that they were so hurt by finding themselves HIV positive yet, they knew that they were faithful to their sexual partners. Some stated that they needed somebody to share the pain with. Some women stated that they did not disclose their HIV statuses out of fear of lack of support and probably domestic violence.

Keywords: *Disclosure, HIV, PMTCT, domestic violence, SWAGAA, antenatal care.*

Introduction and background information

It is well known that individuals diagnosed with HIV often have difficulty disclosing their status to others. This is particularly relevant for women in developing countries (Sethosa & Peltzer, 2005) where they are often economically, culturally and socially disadvantaged and may fear abuse or abandonment once their diagnosis is known and increasing numbers of pregnant women discover that they are HIV-positive during pregnancy. This can be particularly traumatic for a woman. Yet hiding her diagnosis can have serious implications. Disclosure of HIV status involves a process of decision-making, based upon numerous factors.

An HIV Test conducted for PMTCT at VCT centre in Swaziland (AMICAALL –SWAZILAND) **Accessed 05-07-13**

Statistically, developed world rates of HIV status disclosure to sexual partners ranges from 42% to 100%, developing world rates range from 16.7% to 86%; disclosure rates to current and/or steady partners is 49%in developing and in developed countries- (79%). The lowest rates among pregnant women tested in antenatal care (ANC) in sub-Saharan Africa (16.7%-32%).

Medley et al., (2004) identified the following barriers for not disclosing the HIV status among women in developing countries; fear of accusations of infidelity, abandonment, rejection, discrimination and violence, disruption of family relationships, emotional and physical abuse and, fear of loss of economic support from a partner. Barriers stem from an awareness of stigma associated with HIV/AIDS (UNAIDS, 2004). Some research studies show that while fears of disclosure are legitimate, consequences are often less severe than anticipated. Medley's review of disclosure (2004) found few women reported negative consequences and many respondents reported positive outcomes.

Picture adapted from Avert Org. Accessed 12-07-2013

Clearly women must weigh the likelihood of an expected negative reaction with the possibility for a positive outcome when considering to whom to disclose. The researcher explored and described reasons for disclosing and not disclosing to sexual partners among Swazi women who test HIV-positive during pregnancy for a programme on Mother-To-Child Prevention of HIV transmission (PMTCT).

Women waiting for delivery

Picture adapted from Avert Org. **Accessed 12-07-2013**

Methodology

Research design

In this study the researcher employed the qualitative descriptive phenomenological methodology. Phenomenology is a science whose purpose is to describe particular phenomena, or the appearance of things, *as lived experiences* (Streubert & Carpenter 1999:43). It develops an understanding of people's opinions about their lives and the lives of others. It also helps the researcher to generate an in-depth account that will present a lively picture of the research respondents' reality.

Sampling

Convenience and purposive sampling were used in the present study. In convenience sampling, participants are included in the study because they happen to be in the right place at the right time (Burns & Grove 1998:217: Polit&Hungler2007:305). The sample in this study was determined by data saturation and it consisted of 15 women who had tested HIV positive for the PMTCT programme.

Data collection methods

In-depth interviewing

In-depth interviews are usually initiated with a broad or general question. After the interview has begun, the role of the researcher is to encourage the participant to continue talking, using techniques such as nodding the head or making sounds that indicate interest. In some cases, the participant may be encouraged to further elaborate on a particular dimension of the topic of discussion (Burns & Grove 2006:307) by using probes. The interviewer is obliged to follow up cues during an in-depth interview in order to get to the 'true' meaning of a phenomenon. The whole interview was tape-recorded and the researcher abstracted data from the material after the interview was over. In doing so, the researcher analysed the information on the tape and translated the interviewees' responses into meaningful descriptions (Themes and categories).

Results

Graphic demographic presentation

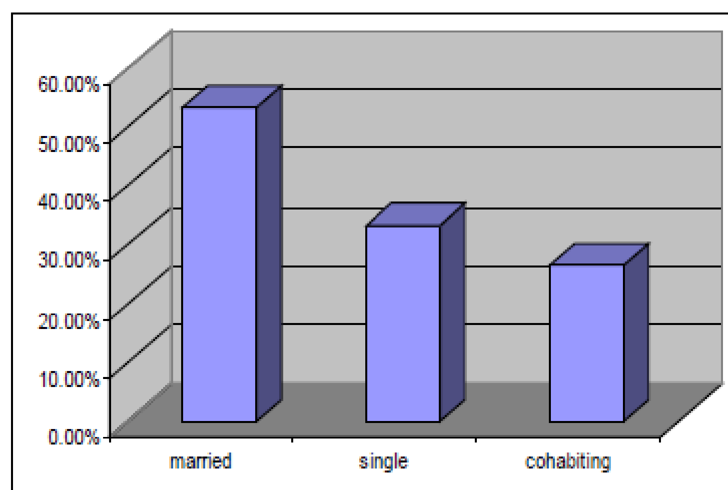

Figure 1. Marital status *n*=15

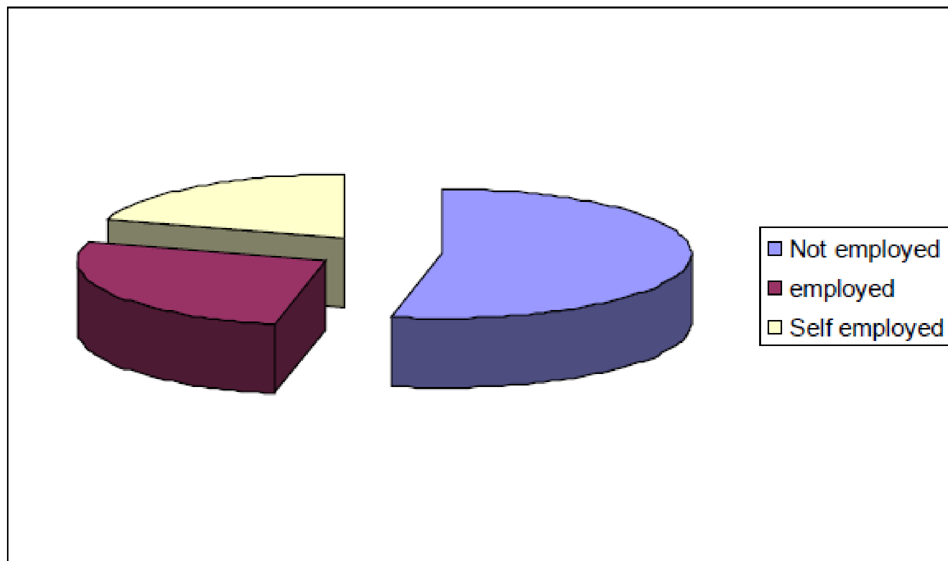

Figure 2. Employment Status of participants n=15

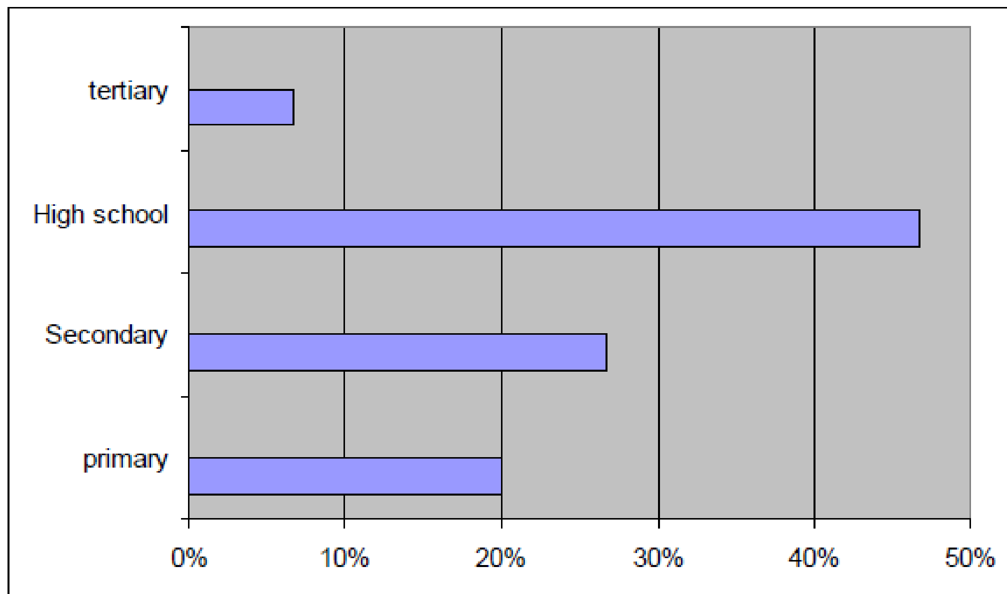

Figure 3. Educational level n=15

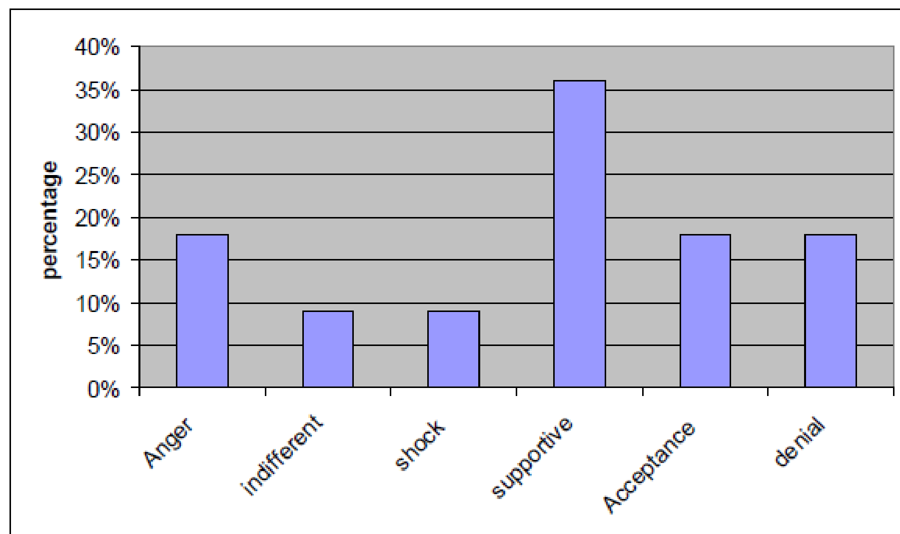

Figure 4. Reactions of partner after disclosure (n=15)

Results

Themes and categories

1. **Disclosure**

Theme 1.1: Anger

Category 1.1.1: Hurt by the diagnosis

Data chunks

- *"I told him that I was HIV positive when I came back from the clinic because I was so hurt; I wanted somebody to share the pain with".*
- *"I was badly hurt; it was not easy for me to accept, I decided to tell him and ask him so that he could explain where it came from".*
- *"I was so sad and I knew it was because of his behavior that I am HIV positive".*
- *"I was haunted by the diagnosis and I needed to cough it out so as to feel better".*

Theme 1.2: Acceptance

Category 1.1.2: Practice safer sex

Data Chunks

- *"I wanted to make him aware and to start using condoms in our relationship".*
- *"I want us to practice safer sex and protect the baby from getting HIV".*
- *"I wanted us to start using condoms and to avoid increasing the infection load"*
- *"I wanted to protect him from getting the HIV from me".*

Category 1.1.3: Protect the unborn baby

Data chunks

- *"I wanted us to protect our baby from getting HIV".*
- *"I wanted him to know so that we could prevent HIV from infecting our child".*
- *"I was concerned about the health of the child".*

2. **Non-Disclosure**

Theme 2.1: Denial

Category 2.1.1 Fear

Data chunks

- *"I am afraid my partner may decide to dump me and I will lose the financial support".*
- *"I don't know how my husband can react towards the diagnosis that uncertainty makes me scared to open up".*
- *"I am afraid that he might decide to leave me because we are not married yet".*

Category 2.1.2 Loss of financial support

- *"Everything might change after disclosure, if I lose him,*
- *I might not get financial support to raise the child".*
- *"I am afraid my partner may decide to dump me and lose the support from him".*

Discussion of results

Disclosing the HIV status to sexual partners, friends and family members can be very difficult. Most prominent reasons for disclosure of the HIV status by pregnant women attended to for the PMTCT programme were that of the need to practice safer sex. Some felt the need to disclose because it would make their sexual partners to protect the unborn babies and to reduce the chances of re-infection. Most women who disclosed stated that they were so hurt by finding themselves HIV positive yet, they knew that they were faithful to their sexual partners. Some stated that they needed somebody to share the pain with, while others said the diagnosis haunted them and wanted to cough it out so as to feel better**.** Some women stated that they did not disclose their HIV statuses out of fear of lack of support and probably domestic violence. According to Worth, Patton, and Goldstein 2008, lack of disclosure has been legally described as fraud, criminal negligence, nuisance and many other charges in addition to jurisdictions. Numerous research studies demonstrate that there are many valid cultural reasons individuals do not disclose their HIV status, such as fear of domestic violence, fear of familial or partner abandonment, and community rejection.

Recommendations and conclusion

There commendations are that programmes and policy approaches should be developed that have been recommended to increase HIV status disclosure rates and support individuals through the disclosure process. If women disclose and experience violence or mention the fear of any abuse during the post-test counseling session as a reason that they are afraid to disclose their HIV status to their partners, HIV counselors should**:** Address this when discussing disclosure, and be prepared to refer these women to domestic violence services like Swaziland Action Group Against Abuse (SWAGAA). The development of support groups for infected women can provide an avenue for ongoing support that may help women work through their disclosure processes. More research is needed to identify disclosure factors so counseling tools can be developed to identify individuals less likely to disclose and counsel them accordingly.

Conclusion

This research has successfully fulfilled the stated objectives and aims. Even though HIV status disclosure is difficult for some women, a significant number of women disclose their status to sexual partners and it is encouraging to note that some men are very supportive to their partners. Therefore women must weigh the likelihood of an expected negative reaction with the possibility for a positive outcome when considering disclosing.

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