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Reproductive health needs of HIV positive women: client perspective

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This study aims to identify the reproductive health needs of HIV positive women from client perspective. A total of 20 women (12 married and 8 unmarried women) participated for serial in-depth interviews after obtaining written inform consent. The study was done from August 2006 to July 2007 in Waibargi Infectious Hospital, Yangon. Age of the respondents ranged from 19 to 43 years. The majority of women in the study had only one sexual partner in their entire life. Over two third of the women were diagnosed after their spouse. Almost all women in the study revealed their HIV status to their spouse immediately after diagnosis. Although all women accepted the positive status, women with children had better perception towards positive living. About half of the women in the study revealed that sexual relation still exist within their relation. Even though dual protection advantage of condom was recognized by women in the study, the gender power inequality to negotiate condom use with their partner was expressed by almost all women in the study. Apart from one woman who intends to have a child all others perceived that it was not fair and just to bring a life when one cannot even take care of one's health. Discrimination and stigma of being positive was more prominent among the unmarried women. This study highlights the need for comprehensive reproductive health care towards HIV positive women whether married or unmarried.

INTRODUCTION

HIV is the fourth largest cause of death globally and the challenge posed by HIV/AIDS is most critical in sub-Saharan Africa and Asia. In South-East Asia, Myanmar, along with Thailand and Cambodia, have been identified by UNAIDS as the three highest priority countries. In the early stages of the pandemic, HIV infection was predominantly among men. But estimates in December 2005 by UNAIDS indicate that about 40 million people are living with HIV of which about 17.5 millions are women.

According to the National AIDS Programme (NAP), UNAIDS and WHO, there were estimated 338911 adults living with HIV at the end of 2005. As sex disaggregated national prevalence rates are currently not available, the sex ratio of 4 HIV infected males to 1 female has been estimated in 2004 by using government sentinel surveillance data of certain population groups. Since the decreasing trend of the sex ratio has been observed in many parts of the world, vulnerability of women being infected had risen in recent decade.

This increasing incidence of HIV/AIDS in women has clearly revealed their vulnerability which may be the consequences of social and economic inequality among women. Many studies have showed that more than 80 percent of women living with the virus were infected by their partners. The risk of mother to child transmission of HIV and subsequently leading to higher rate

of infant death also associated with maternal HIV infection and these issues highlight the need to know more about **"women with HIV infection"** there by reducing the risk not only for the HIV infected women herself but also to her future offspring.

Objective

- To provide information and understanding of the reproductive health needs of HIV positive women from client perspective for effective programming towards HIV positive persons.

MATERIALS AND METHODS

Study Design

A qualitative exploratory study

Study area

The study was conducted in Waibargi Infectious Hospital, Yangon from August 2006 to July 2007.

Data collection methods

Data collection activities were carried out between September 2006 and May 2007. Before starting the actual data collection, information regarding HIV positive women was gathered from Waibargi Infectious Hospital officials, persons working with PLWHA, people affected by HIV/AIDS and various local and government service providers. A broad outline for the In-depth Interview guide was developed.

Interviewers were thoroughly explained about the study's objective and sensitive nature of questioning towards sexuality issues with HIV positive persons. Only female interviewers were trained and used to gather information in this study.

A total of 20 serial In-depth Interviews (IDIs) were carried out with HIV positive women after obtaining a voluntary inform concent. Since the interviews were in-depth and sensitive, majority entail more than one session. Due to the reluctance of tape recording by some of the respondents, note taking was done by the interviewers with permission. On average each IDI lasted about an hour and a half.

Ethical considerations

Ethical permission to conduct this study was sought and obtained from Institutional Ethical Review Committee, Department of Medical Research (Lower Myanmar).

Data analysis

All the IDIs sessions were jotted down by the interviewers. Transcripts were checked and discussed by the interviewers and the principle investigator on a daily basis. The principle investigator coded the findings of the interview according to the themes and sub themes together with the team members. While coding, any unclear phrases or sentences were clarified immediately. All the team members set together and matrix analysis was done manually. Comparisons were made between different people and recurring patterns of themes were noted down. Plausibility to draw any conclusion was observed. Then the team leader combined the information using the thematic analysis approach.

RESULTS

General characteristics of the respondents

A total of 20 women participated in the study. Using the marital status as main dimension, a total of 12 married and 8 unmarried (5 widows and 3 singles) women participated in the study. Age of the respondents ranged from 19 to 43 years. Majority of the women had above secondary school level of education. Six women were graduates.

Testing and perception towards HIV positive diagnosis

Majority of the women in the study had only one sexual partner in their entire life. Knowing the HIV positive result (HIV status) was an unforeseen event in their life. Along with astound and fear, most of the

women felt very negative about their husbands after knowing their status. Being naive and unknowledgeable about the disease and its transmission was regret as described by the women in the study.

"*I was a dutiful housewife, I looked after my children, I was faithful to him and I took care of him well, my family was my life, I hate him, I will never forgive him.*"

(A widow with a child)

Majority of the women in the study were out of the blue when they were told that they were positive. Some said it was like going to hell alive. The first few months were very painful as described by most of the women.

"*I can recall those days and I was very grateful that I was able to overcome myself. It's like a death sentence and getting to hell alive."*

(A married woman with 3 children)

With the belief of the religious teaching of '*Kan*' (ကံ) and '*Shay kutho*' (ရှေးကုသိုလ်) mostly expressed by many women meaning that this is their fate and they must have done something bad in their preceding life. Almost all women in the study were willing and accepting the condition as part of their life.

One educated woman described her incidence as "love blindness". She was very well brad and educated and she had ample knowledge about the disease. But when she got married she was madly in love and she had totally elapsed.

" Love is very powerful, at least for me at that time, but when I found out that I was positive during my pregnancy, I blamed my self first….. because…., why did I believe him…..? was he worth believing? …, I don't know."

(A graduate woman)

The pregnant women in the study were diagnosed as HIV positive when they attended the pre-natal clinic at Central Women's hospital. They had no prior discern about the disease. They did not have any knowledge of the blood testing procedures. The results were given to them together with their family members. All were shocked at the time of diagnosis. According to the participants they did not get any type of counseling before the test from anyone.

"I went to the hospital with my husband and they gave us the paper and told me to go and see the doctor in the room. The doctor asks what my husband does and she said I have the HIV virus. "

(A pregnant woman)

Disclosure of HIV positive status

For majority of the women, it took sometime to believe and accept their own HIV status. Over two third of the women in the study were diagnosed after their spouse. Almost all women in the study told their status to their husbands immediately after they were diagnosed.

"*It's because of him, of course he should be the first to know.*"

(A married woman)

Disclosure of the HIV positive status to others apart from their spouse depends greatly upon their family structure, values and how they weigh the perceive consequences towards themselves and their family. Some of the HIV positive women said that they dare not to disclose their status to friends or close relatives out of fear and guilt and being blamed not only to her but also to her husband and children as well. Reluctance to tell older parents was revealed by most of the participants. Disclosure to the community especially to the closest neighbor was regarded as last by most of the respondents.

"They are already old and I don't want them to live with shame and sadness because of me, so I told my sister not to tell them"

(A married woman)

"We keep it to ourselves, it's our life and they will not and cannot do anything for us,

so why they tell which for sure they will disgrace us."

(A married woman)

Revealing the HIV status was more difficult for a single woman than for a married woman. Women are expected to be demure and innocent before marriage. Value towards virginity is very high for a woman. Premarital sexual activity is regarded as a socially unacceptable behavior. Shame and disgrace for being sexually active puts a loosing face not only to the affected female but also to her family as well. Social stigma attached to HIV/ AIDS as a sexually promiscuous disease often enhances the single sexually active woman not to disclose her status.

"I don't intend to tell anyone especially my parents and close friends. I'm really scared that they would find out, it will be a disgrace for my parents."

(An unmarried woman)

Aspiration to live on as a positive person

Women in the study had more or less positive aspiration towards living with HIV. Determined and stronger aspiration to live was seen among positive women with children. Their responsibility as a mother and a care taker for their children was highly expressed by all the women.

"*I need to be tough, strong and healthy so that my children will grow up well.*"

(A woman with 3 children)

This intention to live on was also strongly seen among the mother who was recently diagnosed after her husband's death.

"*I have my children. He died because he was bad. As for me I still have to live for my children. I am not ashamed, I didn't do anything wrong.*"

(A 30- year-old widow with 2 children)

Sexual and reproductive life after diagnosis

About half of the women in the study revealed that they had sexual relations with their partners after diagnosis. But for women they described that desire for sexual activities declined dramatically after diagnosis. For majority of the Myanmar women, sexual life starts along with marriage. Being married means submitted to a life time partner in her social, economical and environmental world. She gives herself to him with love, faith, commitment and is intended to stay with him in time of happiness as well as in times of difficulties. As she is submitted to her husband with love, the power to deny no to sex is not easy. This means that women in general have not enough power to resist to their partner's need regarding sex. Majority said even though they had no feelings for sex and lack of intentions, the fulfillment of the partner's need for sexual activity had to resume after about 6 months to one year. Thus desire towards sexuality was more or less partner driven.

"*Both of us are positive, I have no desire since I know that I was positive. But because he wants it, and I am his wife, I had to give him.*"

(A married woman with children)

Sexuality of unmarried HIV positive persons

Single unmarried females in the study were very regretful and had self blames and mixed feeling towards being sexually active without being married. Social norms that accept pre-marital sexual relationship in men and the social stigma being attached to being sexually active before marriage for women often leads towards non-disclosure for unmarried women. One of the females had only one sexual encounter in her whole life time. She was about to marry him because of the happening as she describes.

"*He died of AIDS. So I went secretly to test myself and I found out that I was also positive (crying). Why me, my life is over.*"

(An unmarried woman with a deceased partner)

"*As I am a single, how would I show my face? People will assume I am a loose girl.*"

(An unmarried woman)

Marriage and having children

The unmarried women in the study said marriage was out of the question for them. Apart from one woman who intended to have a child, all others perceived that it's not fair and justice to bring a life in when you cannot take care of yourself.

"*Up to now I have no intention to get married. It's not fair to give 'misery' (ဒုက္ခ).*"

(An unmarried woman)

"*Even though we both are positive, I love children and there is still a chance of having a negative child. I want to take that chance.*"

(A graduate woman)

Family planning including dual protection

Knowledge regarding family planning method among HIV positive women in the study was limited to condoms and only a few female mentioned about pills and injectables. Two married female with children also said that sterilization was a family planning method for HIV positive persons.

All the female knew that condoms were the most appropriate method for all the positive individuals regardless of their family planning intentions. They also mentioned that, as condoms are the only method that protects against HIV and other sexually transmitted infection, all providers recommend and encourage them to use condom. They also said that the providers rarely mentioned methods other than condoms to them.

"*Sayama always told me to persuade my husband to use condom. She also provided me with condoms.*"

(A married woman with one child)

Pattern of condom use

When inquiring about condom use and regularity, married women in the study said that they always try to insist and persuade their partners to use condom. But non-condom use during the sexual act was experienced by almost all married women in the study. Together with '*thanaseik*' (သနားစိတ်) meaning having a soft heart, love and commitment, the gender power dynamics within the sexual encounter often conquer the knowledge and awareness of the use of condom among HIV positive women in the study.

"*When he started saying it is so pity that as a human, I cannot have children, his face and expression conquered my decision of using a condom.*"

(A woman with 2nd marriage)

Prevention of Mother to Child Transmission (PMCT)

The pregnant women in this study had intended pregnancies. All were very happy with being pregnant before the diagnosis was made. They went to the hospital to take regular antenatal care service during their second trimester. They had no prior knowledge about the PMCT services and maternity care. All of the pregnant women in the study did not receive any pretest counseling prior to the HIV testing.

"*I didn't know anything; they said blood test has to be done, so I took the blood test*"

(A pregnant woman)

One of the pregnant women had received proper post-test counseling regarding prevention activities about her pregnancy and child birth.

"*I now regret that I was pregnant, but no choice, it's my fate*".

(A pregnant woman)

Stigma and discrimination towards PLWHA

When the open question on "who do you think would be the most discriminated and stigmatized, a man or a woman?" Their opinions and answers were more or less similar. They regarded the disease as very shameful and disgrace. They said both men and women would be discriminated and stigmatized because of the positivity but the suffering compounded more to the woman in her social life. She faces tough time

because she not only bears the discrimination and stigma but also has to carry on the role as a care given for her infected partner and children. The discrimination and stigma of being HIV positive without being married had a significant impact on women.

"*No matter who stigmatize or discriminate. Because we are women we are bound to take care of our husbands and children. We bear more burdens.*"

(A married woman)

DISCUSSIONS

As HIV/AIDS in Myanmar is considered an advanced epidemic, people living with HIV virus at the end of 2005 was estimated to nearly forty thousand by the National AIDS Programme in 2006. As majority of the infected people are within the reproductive years, this study aims to shed light on the future care and support towards people living with the HIV/AIDS in consideration of their reproductive intention and needs from a female perspective.

All the married women living with HIV in this study revealed that they were infected from their partners. It was beyond their expectation and knowledge within marriage that this would happen. Their faithfulness compounded by little knowledge about the disease had made them to be HIV positive persons.

The gender inequalities are seen in which women generally are less able than most men to decide over their bodies and lives, which increases their vulnerability to HIV/ AIDS. This finding indicates that lack of knowledge towards the disease and being faithful to their life time partner is of no protection for such women.

In this study, majority of the women had only one sexual partner in their entire life that being vulnerable to HIV can simply mean married to a potentially or already infected partner. Therefore education regarding pre-marital counseling and voluntary counseling and confidential testing of both partners before marriage should be encouraged to the never married people before they become sexually active.

Disclosure or revealing the positive status about the infection was much harder for unmarried participants than married participants. The never married sexually active women bears a greater burden of living as a HIV positive person. Being sexually active for an unmarried male is usually regarded as a manly behavior. But for the unmarried female the social expectation towards virginity and sexual exposure before marriage put them as disgrace and shameful. This social norm and double standard given to men may enhance more women with HIV positive status to not disclose their status to anyone including their potential partners. Therefore people working with PLWHA should consider the negative impact faced by the HIV/AIDS infected never married women and find ways and means to overcome these barriers.

Even though dual protection advantage of condom was recognized by women in the study, the gender power inequality to negotiate condom use with the partner was expressed by almost all married women in the study. As condoms and abstinence were the most commonly discussed and encouraged methods regardless of the intention of reproduction for the HIV positive persons, the role of the gender power relation should also be taken into consideration by the providers. Therefore, programmes and providers working with HIV infected people must recognize the difficulty of condom use by women and help women to develop the necessary skills to negotiate condom use.

In this study the area on PMCT is covered insufficient since there were only three pregnant women. Although the PMCT programme has been widely carried out by both government and non-governmental (local as well as international) the findings form this study highlights that the PMCT programme should expand on covering a

wide range of women especially those women from inaccessible areas with the programmes.

Even though this study's primary focus was on reproductive intentions, issues regarding stigma and discrimination of PLWHA were also addressed. As of other studies, the discrimination and stigma were most prominent among the unmarried women. In order to give comprehensive care towards people living with HIV/AIDS whether married or unmarried programmes should take into great consideration of not only their perceived reproductive intentions but also towards discrimination and stigma issues which cannot be separated.

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