

Percentages, Process, and Patterns of HIV Disclosure Among the Spouses of HIV-Infected Men in South India

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Abstract

Most studies have described the outcome of HIV status disclosure rather than the process of disclosure. Hence, a study was conducted among 201 women who accompanied their spouses and children to 3 hospitals at Chennai and Vellore, Tamil Nadu, India, during January to June 2007. Majority of the respondents were sero-positive (69%) and marriage was the only risk factor for them. Of 201 women, 49% did not know the reason for their husbands' HIV infection. Confidentiality of the patient was often breached during disclosure as family members were drawn into the process without consulting the patient. Only for 117 (50%) respondents, HIV diagnosis was disclosed directly by the health providers. There was a considerable delay for men in disclosing their HIV status to their spouses. Apart from the spouses, 122 (61%) shared their diagnosis with other family members. Disgrace to self and family (54%), fear of discrimination (27%), and fear of rejection (9%) were reported for nondisclosure.

Keywords

disclosure of HIV status, wives of HIV-infected persons, Tamilnadu, India

Introduction

Disclosure is an important interpersonal phenomenon that has received considerable research attention in HIV. Individuals who are aware of their HIV sero-status are frequently confronted with the important difficult decision of whether to disclose one's sero-status to others. Earlier studies have shown that perceived stigma and discrimination are at times more powerful than enacted stigma and discrimination in discouraging people from being open about their own sero-status and in accessing treatment and support.¹⁻⁴ An Indian study² found that although a majority of those who had shared their HIV status with their families received care and support, it was largely men rather than women who qualified for such care. Women are usually the innocent victims of HIV infection and they are blamed for their husbands' infection also. They are afraid that disclosing their HIV-positive status may result in physical violence, expulsion from their home or social ostracism, or their property being seized after their partner died.⁵⁻⁷ Hence, it will be more appropriate to get information from the wives of HIV-infected men, who form the suppressed and oppressed group in Indian society. Besides, most studies have analyzed the outcome of HIV disclosure rather than the process of disclosure. Hence, this study aims to examine the process of HIV-related disclosure and its patterns, reasons for

nondisclosure, and reactions of HIV disclosure among the spouses of HIV-infected men in South India. We have tried to collect the information by asking questions about disclosure by whom, how, and when from the wives of HIV-infected men who attended 3 hospitals at Chennai and Vellore in Tamil Nadu, India.

Methods

The respondents were recruited from Tuberculosis Research Centre (TRC), Government Hospital for Thoracic Medicine (GHTM), Tambaram, Chennai, and Vellore Government Medical College Hospital (VGMCH), Vellore, and included those women who accompanied their spouses and children for HIV

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Table 1. Socioeconomic Background of the Respondents

Baseline Characteristics	Number of Respondents	%
Age		
21-40 years	194	96
>40 years	7	4
Place of residence		
Urban	80	40
Suburban	30	15
Rural	91	45
Type of family		
Nuclear	144	72
Extended	13	6
Joint	44	22
Education		
Illiterate	51	25
School educated	144	71
Higher studies	6	3
Occupation		
Employed	82	41
Unemployed	3	2
Home maker	116	57
HIV status		
Sero-positive	138	69
Sero-negative	55	27

treatment during January 2007 to June 2007 after screening them per the inclusion criteria. A total of 201 married women were included for the study. The inclusion criteria were that women respondents should be aware of their husbands' HIV status and they should be living with them. A pretested, semi-structured interview schedule consisting of both open as well as closed questions was used to collect data. The study participants were interviewed by the researcher in a private room and the participants were given the informed consent agreement to read or to be read, which provides information on the study and the risks and benefits of their participation. Participant confidentiality was assured in the informed consent agreement.

Data Analysis

The analysis of the data was done using the Statistical Package for Social Sciences (SPSS), version 15.0. The data were validated and analyzed. General descriptive statistics such as frequencies were calculated. Cross-tabulations were done to probe further into the impact of HIV infection on families, and charts were used for the description of the data.

Results

Sociodemographic Characteristics of the Participants

Table 1 shows that 96% of women belong to the productive age group of 20 to 40 years. Of 201 respondents, 45% lived in rural areas, 40% lived in urban areas, and 15% lived in semiurban areas. Majority of the respondents (72%) lived in nuclear families, 6% in extended families, and 22% in joint families and the average family size was 4.1. Majority of the women

respondents (67%) were educated up to high school, 51 (25%) did not have any formal education, and only 16 (8%) had higher education. Of 201 respondents, 118 (59%) women were housewives and 82 (41%) were employed.

Respondent's Knowledge About the Source of HIV Infection

Of 201 women, 49% did not know the reason for their husbands' HIV infection. Sixty-six (33%) women perceived that their husbands might have contracted the infection through multiple heterosexual unprotected contact before or after marriage, 14 (7%) frequent unsterilized injections, 7 (3%) receiving blood during accidents or surgeries, 3 (2%) injective drug use, and few women reported tuberculosis (TB), illicit liquor, contact with HIV-infected friend's blood, location of the house on the gutter, and heat as the reason for HIV infection.

HIV Disclosure by Health Care Providers

The process of disclosure includes how the first disclosure of HIV status takes place in the diagnostic centers and then how the diagnosed persons disclose their HIV status to their spouses and other family members subsequently. Of 201 women respondents, 138 (69%) were sero-positive and they reported that they were infected from their husbands only. The disclosure of HIV status was made by the doctors usually, sometimes by the laboratory technicians and nurses, and in few occasions respondents had come to know from the medical reports also. For half of the HIV-positive persons, HIV diagnosis was disclosed directly, whereas for the other half, the disclosure was done to others, which included spouses (39%), siblings (5%), parents (3%), and in-laws (3%). Among 55 (27%) HIV-negative women, the disclosure occurred mainly by their husbands.

On analysis of data, it was found out that 152 (76%) men, 42 (21%) women, and 7 children (3%) were diagnosed first as sero-positive. Of 152 men (spouses of the respondents) who were diagnosed first, the disclosure was made to 64 men (42%) directly whereas among 42 women respondents who were diagnosed first, the health care providers revealed the diagnosis to the individuals concerned for 38% only. Chi-square test was done to find out the gender difference in first HIV disclosure by the health providers. The results showed that the difference between men and women was not statistically significant (Figure 1).

Disclosure to Others

Of 201 women, 122 (61%) reported that they disclosed their diagnosis of HIV to others whereas 75 (37%) did not disclose it to anybody. For 4 (2%) women, the disclosure was done to others and they came to know about their HIV status from them. Among 122 women who had disclosed to others, majority had disclosed their/spouse's HIV status to their natal families, which led to financial and social support later.

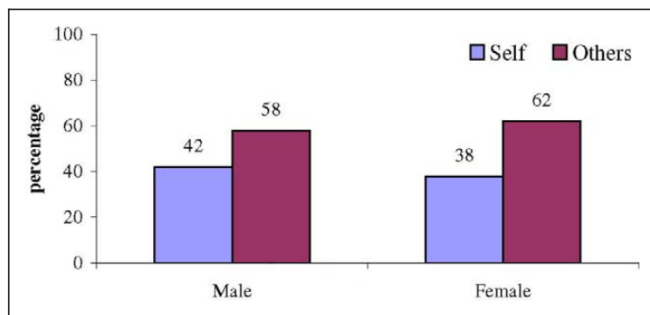


Figure 1. Genderwise HIV disclosure by the health personnel.

Initial Reactions of HIV Disclosure

The disclosed group of respondents (122, 61%) were further asked about the reactions from their family members/close relatives on hearing their/spouse's HIV status. Most respondents reported multiple responses. Of 122 women, 72 (59%) respondents had reported shock on the part of their family members on hearing the news, and 52 (43%) of them had empathized. About 11 (9%) of the respondents had been abused and cursed, 12 (10%) had expressed disbelief about the HIV infection, and 34 (20%) had not shown any difference.

Reasons for Nondisclosure

Most of the 75 respondents who did not disclose their HIV status to others reported multiple reasons for their nondisclosure. These included disgrace to self and family (49%), fear of discrimination (43%), and fear of rejection (20%). Few had given reasons such as that their family members/close relatives could not understand about HIV/AIDS, no intention to hurt or scare them, and so on.

Discussion

Of 201 women, 49% did not know the reason for their husbands' HIV infection. Sixty-six (33%) women perceived that their husbands might have contracted the infection through multiple heterosexual unprotected contacts before or after marriage. The fact that half of them did not know about their husbands' probable mode of infection gives an insight into the sexual ethos of the society where men could live with multiple sexual partners and women could not question the sexual behavior of their men.

Our study respondents had reported high rate of disclosure without the individual's consent, and in most cases, the breach of confidentiality occurred through health professionals. The doctors made the disclosure usually, sometimes the laboratory technicians and nurses, and in few occasions respondents had come to know from the medical reports only. For half of the 201 respondents, HIV diagnosis was disclosed to the individuals concerned, whereas for the other half, the disclosure was done to others (wives, siblings, parents, and in-laws). For men who were diagnosed first, the disclosure was made to him directly for 42%, whereas for women, the diagnosis was

revealed to her directly for 38% only. For 62% of women, the disclosure was done to others without getting their consent before disclosure. Positive test results were often shared with the family members accompanying the patient. The principle of confidentiality was often disregarded altogether in the case of women, the less educated, and the poor.

In a study done at Bangalore, South India,⁸ the disclosure without consent was done in 35% of 68 participants and in the majority of the situations, this happened by health professionals (75%) revealing the results to family members. Similarly, another prior research at Pune⁹ found out that private practitioner's communication with their patients about HIV is prescriptive rather than shared and falls considerably short of best practice standards on consent, counseling, and confidentiality as upheld in national guidelines. Confidentiality of the patient is often breached during disclosure, as family members are drawn into the process without consulting the patient. This highlights the need to focus on ethical aspects of HIV-related disclosure among various treatment settings.

The importance of informed consent, pretest and posttest counseling, and the part of the providers is being stressed in all programs. However, whether it is being practiced needs to be stressed periodically. This is important, as people who receive counseling are better able to make a successful adaptation to their situation.¹⁰ HIV counseling and testing services have general information that is key to the national AIDS prevention and care strategies of many developed countries, including the United States.¹¹

Of 201 women respondents, 138 (69%) were sero-positive and they reported that they were infected from their husbands only. Single partner heterosexual sex with their husbands was the only HIV risk factor for the women. Hence, HIV prevention and intervention strategies need to focus on married, monogamous Indian women whose self-perception of HIV risk may be low but whose risk is inextricably linked to the behavior of their husbands. Besides, one third of 201 women had not disclosed their/husbands' HIV status to others due to their fear of stigma and discrimination. Disclosure of HIV infection can lead to important social support to mitigate the negative effects of stress. Hiding one's sero-status may not only preclude HIV-related social support and benefits but may also have direct negative effects on disease progression for HIV-positive individuals. Women with HIV/AIDS are hesitant to access health care for fear of breach of confidentiality, perceived stigma from provider, and are reluctant to take medications that identify them as being ill.^{12,13} Hence, HIV counseling needs to be gender sensitive and it needs to focus on disclosure issues more in future. In addition, our study has shown that training of health care providers should be taken as a priority, as the stigmatizing experiences with them have a devastating impact on the lives of patients living with HIV/AIDS (PLWHAs). More awareness about pretest counseling, informed consent, posttest counseling, and the importance of privacy and confidentiality should be created in the health facilities. Community-based programs to reduce stigma associated with HIV/AIDS is another approach to facilitate HIV disclosure.

Declaration of Conflicting Interests

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