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Original Research Article

Disclosure of HIV status by people living with HIV/AIDS in tertiary care hospital in Western Maharashtra

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ABSTRACT

Background: Disclosure is a planned and selective behavior that responds to the balance of potential risks and benefits of secrecy and disclosure of the person living with HIV. The disclosure of HIV status to sexual partners, family or friends, has been shown to be a potent stressor, as persons living with HIV/AIDS might fear negative reactions such as blame, rejection or violence. This study was carried out with an aim to study the patterns of HIV status disclosure and the problems related with it among the HIV positive patients admitted in a tertiary care hospital in Western Maharashtra.
Methods: A cross-sectional descriptive, hospital based study carried out in a tertiary care hospital of Western Maharashtra from 01 October 2008 to 30 September 2010. A total of 92 consenting respondents admitted in the hospital were administered a pre tested semi-structured questionnaire to collect the data. The results were analysed using SPSS Ver 16.0.
Results: Out of 74 married HIV positive individuals who had a chance to disclose their sero-status to spouse, 64 (86.5%, 95% CI-78.7% to 94.29%) voluntarily disclosed their HIV status to spouse while a small number i.e. 10 (13.5%, 95% CI- 05.71% to 21.29%) did not disclose their HIV status to spouse.
Conclusions: This exploratory analysis suggests the need for tailoring interventions for improving disclosure decisions making and outcomes. Institutionalized measures need to be enforced judiciously to assist the HIV positive individuals to reveal their status to their wife and other members of their social group.

Keywords: Disclosure, HIV, Spouse

INTRODUCTION

Acquired Immuno Deficiency Syndrome (AIDS) a fatal disease is caused by a Retrovirus belonging to the Lentiviridiae group known as HIV (Human Immunodeficiency virus), a single stranded RNA virus. The disease was found to breakdown the body's immune system, leaving the victim vulnerable to a host of life threatening opportunistic infections, neurological disorders or unusual malignancies.[1]

The AIDS Epidemic, since its discovery in 1981, is spreading all over the world breaking all social, cultural and geographical barriers. In 2008 alone, 33.4 million (31.1 million-35.8 million) people were living with HIV, 2.7 million (2.4 million-3.0 million) people became infected with the virus, and 2.0 million (1.7 million-2.4 million) people died of HIV related causes.[2]

In many regions of the world, new HIV infections are heavily concentrated among young people (15-24 years of

age). Sub-Saharan Africa continues to bear the brunt of the global epidemic. In 2008, Sub-Saharan Africa accounted for 67% of HIV infections worldwide, 68% of new HIV infections among adults and 91% of new HIV infections among children. The region also accounted for 72% of the world's AIDS-related deaths in 2008.[2] In the past two years, the number of people living with HIV increased in every region of the world. The most striking increases have occurred in East Asia and in Eastern Europe and Central Asia.[2]

The first HIV infected person was detected in India in 1986. The HIV/AIDS epidemic has spread like wildfire since then and today it is estimated that there are 2.31 million (1.8 - 2.9 million) Indians living with HIV.[3,4] The estimated adult prevalence in the country is 0.34% (0.25% to 0.43%) and it is greater among males (0.44%) than among females (0.23%). The prevalence rate of HIV infection in the country has stabilized over the last few years.[4] Heterosexual intercourse is the primary mode of transmission of HIV in India.[4-6] Studies in India have shown that married monogamous women are at great risk for HIV infection from their husbands who may engage in high-risk behaviours.[7-9]

The prevention and control of Human Immunodeficiency Virus (HIV) infection depends on the success of strategies implemented to prevent new infections and to treat currently infected individuals. Voluntary HIV testing and counseling can serve both the goals, by enabling healthy individuals to remain uninfected and those infected to plan their future and to prevent HIV transmission to others.[10] Disclosure of HIV status to one's sexual partner is an important prevention goal emphasized by the WHO and CDC in their protocols for HIV counseling and testing.[11]

The disclosure of HIV status to sexual partners, family or friends, has been shown to be a potent stressor, as persons living with HIV/AIDS might fear negative reactions such as blame, rejection or violence.[12-14] However, negative outcome following disclosure is seen in few cases (less than 12% males and less than 17% females).[15] It is therefore important that such individuals reveal their HIV positive status to their spouse and ensure only protected sexual intercourse. Disclosure offers a number of important benefits to the infected individual and his wife or sexual partner and to the general public. Disclosure of HIV positive status to one's sexual partner is associated with less anxiety and an increased social support. It may lead to improved access to HIV prevention, treatment, opportunities for risk reduction and planning for the future.[14,15]

Disclosure is a planned and selective behavior that responds to the balance of potential risks and benefits of secrecy and disclosure of the person living with HIV. The progression of HIV may precipitate disclosure because of visible signs of disease or an urgent need for emotional support.[16]

Despite such large benefits derived from HIV status disclosure both to HIV infected individual as well as to his spouse, there seems to be a relative lack of studies on various aspects of HIV status disclosure and it's outcomes in India.

Objective of the study was to study the prevalence of HIV positive personnel disclosing their HIV status, to study the patterns of HIV status disclosure and to study the problems related with HIV status disclosure.

METHOD

A cross-sectional descriptive study was carried out in a Tertiary care hospital of Western Maharashtra from 01 October 2008 to 30 September 2010. The study population comprised of all HIV positive male admitted in tertiary care hospital who had been HIV positive for at least six months.

All HIV positive patients admitted to the Hospital meeting the selection criteria and who consented to be part of study were included in the study as and when they were admitted during the period of one year from 01 January 2009 to 31 December 2009. A total of 92 HIV Positive individuals who met the criteria and consented to be part of study were included. HIV positive males who did not consent to be part of the study and those who have been positive for less than six months were excluded from the purview of the study.

The data was collected from all selected study participants through an interview technique after explaining the purpose of the study. An informed written consent was obtained before interview. A semi-structured questionnaire was administered ensuring the confidentiality of the information provided by the patients. The questionnaire was pre-tested and suitably modified based on the responses received.

Study participants were broadly classified into two groups- married and unmarried; further married individuals were classified into Voluntary disclosure to spouse (voluntarily disclosed or not) and Involuntary disclosure to spouse (disclosed by others without study subject's concurrence). Disclosure to others (excluding wife) was analyzed for all the study subjects.

The semi-structured questionnaire was divided into four different sections, all of which needed to be completed individually for each patient by the researcher himself. All questions were self - explanatory. Options were provided in almost all the questions which only needed to be ticked or the blank space completed by the researcher based on the most appropriate responses of the patient. The options were not revealed to the patient to avoid any bias. Any queries were answered by the researcher without any attempt to influence the answer. The questions of the questionnaire were in the four parts; Part I: the socio-demographic details of the respondent, Part

II: the circumstances of the HIV test on the respondent, Part III: the disclosure details and problems associated with the disclosure, Part IV: Other associated information including knowledge of HIV and sexual behaviour of the individual.

Data analysis

The questionnaires were collected and checked for adequacy and completeness. The responses were coded and entered on the computer using Software package Microsoft Office Excel version 2007. Validation of data was done after completion of data entry. Data was then imported to both Microsoft Office Access version 2007 and SPSS version 16.0 (2007) and subjected to statistical analysis.

RESULTS

Overall 92 HIV positive patients meeting the criteria were admitted in tertiary care hospital during the period 01 January 2009 to 31 December 2009. All these 92 patients consented to be part of the study and hence were included in the study. Demographic characteristics of the study patients is as depicted in Table 1.

Table 1: Demographic characteristics of study participants.

Attributes	Categories	Numbers	%
Age (years)	≤30	16	17.39
	31-40	60	65.22
	41-50	13	14.13
	>50	03	3.26
	Total	92	100.00
Education	Under-matric	18	19.56
	Matric	53	57.61
	Intermediate	14	15.22
	Graduate	06	6.52
	Post graduate	01	1.09
	Total	92	100.00
Marital status	Unmarried	08	8.70
	Married	84	91.30
	Total	92	100.00
Religion	Hindu	81	88.04
	Christian	05	5.44
	Sikh	06	6.52
	Total	92	100.00
Usual place of residence	Rural	67	72.83
	Urban	25	27.17
	Total	92	100.00
State of residence	High prevalence states (Six)	45	48.91
	Other states	45	48.91
	Nepal	02	2.18
	Total	92	100.00

Majority of subjects i.e. 60 (65.22%) were aged between 31-40 years followed by 16 (17.39%) and 13 (14.13%) subjects belonged to the age group of <30 years and 41 to 50 years respectively. Only 03 (3.26%) subjects were in the age group of >50 years. The mean time since diagnosis of HIV for these 92 individuals was 42 months (95% CI 35.17 to 48.13), range being 06 months to 150 months.

Of these 92 cases, 84 individuals were married and 08 were unmarried. Of the 84 married individuals HIV status of 10 individuals was disclosed to their spouse by others without the consent of the individual. Out of the remaining 74 married individuals 64 voluntarily disclosed their HIV positive status to their spouse while the other 10 individuals did not disclose their HIV status to their spouses (Table 2).

Table 2: Profile of the study subjects.

Profile of the study subjects	Frequency	%
Voluntarily disclosed to spouse	64	69.57
Did not disclose to spouse	10	10.87
Involuntary disclosure to spouse	10	10.87
Unmarried	08	8.69
Total	92	100.00

Table 3: Details of individuals who voluntarily disclosed their HIV status to wife as per time taken.

Time taken for disclosure to spouse	Number	%
Same day	09	14.1
1-7 days	09	14.1
8 days-1 month	19	29.7
1-3 months	15	23.4
3-6 months	07	10.9
>6 months	05	7.8
Total	64	100.0

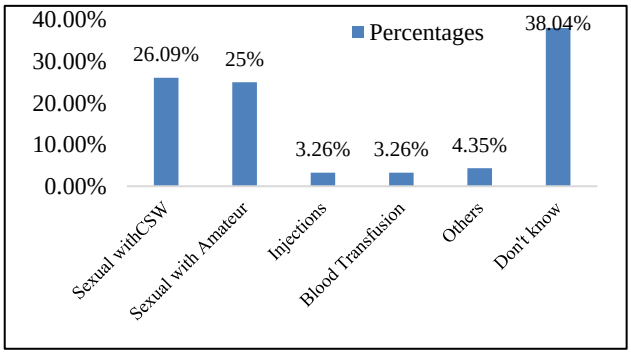

Figure 1: Percentage distribution of HIV positive personnel as per mode of acquiring HIV in the study subjects.

The study revealed that the predominant mode of acquiring HIV in the study subjects was through sexual route (47 out of 92) while a large number of individuals didn't disclose their mode of acquiring HIV (35 out of 92). Other modes of acquiring HIV as told by study subjects were blood transfusion (3.26%), injections (3.26%). 04 individuals (4.35%) thought that they acquired HIV through sexual intercourse with their wife (Figure 1).

Out of 74 married HIV positive individuals who had a chance to disclose to spouse, majority 64 (86.5%, 95%CI-78.7% to 94.29%) voluntarily disclosed their HIV status to spouse while a small number i.e. 10 (13.5%, 95%CI-05.71% to 21.29%) did not disclose their HIV status to spouse.

Of the 64 HIV positive individuals who disclosed their HIV status to spouse maximum numbers 19 (29.7%) disclosed between '08 days to 1 month' of HIV Positive status followed by 15 (23.4%) who disclosed between '1 to 3 months'. Nine (14.1%) individuals disclosed their status on the 'same day' and same number of individuals disclosed between '1 to 7 days'. Seven (10.9%) of individuals disclosed their status between '3 to 6 months' after diagnosis and very few individuals i.e. 05 (7.8%) disclosed 'more than 06 months' after diagnosis (Table 3).

When separately taken into consideration, 07 HIV positive individuals out of the total 92 individuals got married after diagnosis of HIV. However, 04 (57.1%) individuals disclosed their status to their would be spouses before marrying while 02 (28.6%) individuals disclosed their status after marriage and the other 01 (14.3%) individual never disclosed his HIV status to his spouse.

Maximum number of HIV positive individuals (20.7%) voluntarily disclosed their status to brothers or sisters followed by colleagues (19.6%) while least favoured for disclosure were other relatives and friends (13.0% each). 16.3% of HIV positive individuals voluntarily disclosed their status to their parents.

Out of total 84 married individuals only in 10 cases (11.9%) wife came to know about HIV status of individual from other sources without concurrence of the HIV Positive individual. Out of these 10 cases in majority i.e. 07 cases (70%) medical staff was responsible for disclosure of HIV positive status to the spouse. In 02 cases (20.0%) Office colleague and in 01 case (10.0%) employer of the individual was responsible for disclosure of HIV positive status to the spouse.

Majority of the individuals 46 out of 64 (71.9%) preferred to disclose to their spouse in person while 18 (28.1%) disclosed their status to spouse on telephone. Only 03 (4.7%) individuals took assistance of somebody for disclosure to spouse while all others i.e. 61 out of 64 (95.3%) preferred to disclose themselves without assistance. Out of the 03 who took assistance, 02 individuals took the help of a relative while 01 individual took the help of Doctor for disclosure of HIV status to wife.

Fischer's test was used to examine the significance of association between voluntary HIV status disclosure and time taken for voluntary disclosure of HIV status to spouse with respect to various attributes of the individual (Tables 4 and 5). Voluntary disclosure to spouse and time taken for voluntary disclosure was found to be significantly associated with HIV positive individuals on ART.

Table 4: Distribution of voluntary HIV status disclosure to spouse with respect to various attributes of the individual.

Attributes		Voluntary disclosure of HIV status to spouse		Fisher's exact test p value
		Yes (%)	No (%)	
Age (years)	≤30	08 (80.0)	02 (20.0)	0.616
	>30	56 (87.5)	08 (12.5)	
Educational Status	Matric and below	48 (84.2)	09 (15.8)	0.436
	Above matric	16 (94.1)	01 (5.9)	
Usual place of Residence	Rural	50 (87.7)	07 (12.3)	0.687
	Urban	14 (82.4)	03 (17.6)	
Years of marriage	≤10	31 (91.2)	03 (8.8)	0.326
	>10	33 (82.5)	07 (17.5)	
Staying with family	Yes	17 (94.4)	01 (5.6)	0.425
	No	41 (83.7)	08 (16.3)	
On ART	Yes	48 (91.2)	03 (8.8)	0.008
	No	16 (82.1)	07 (17.9)	
Post-test counseling	Yes	61 (87.1)	09 (12.9)	0.447
	No	03 (75.0)	01 (25.0)	

Table 5: Distribution of time taken for voluntary disclosure of HIV status to spouse with respect to various attributes of the individual.

Attributes		Time taken for voluntary disclosure to spouse		Chi square, df, (p value)
		≤1 Month (%)	>1 Month (%)	
Age (years)	≤30	19 (55.9)	15 (44.1)	0.111, 1,
	>30	18 (60.0)	12 (40.0)	0.739
Educational status	Matric and below	27 (56.2)	21 (43.8)	0.192, 1, 0.661
	Above matric	10 (62.5)	06 (37.5)	
Usual place of residence	Rural	30 (60.0)	20 (40.0)	0.448, 1, 0.503
	Urban	07 (50.0)	07 (50.0)	
Years of marriage (years)	≤10	16 (51.6)	15 (48.4)	0.950, 1, 0.330
	>10	21 (63.6)	12 (36.4)	
Staying with wife	Yes	13 (76.5)	04 (23.5)	1.673, 1, 0.196
	No	24 (58.5)	17 (41.5)	
On ART	Yes	32 (66.7)	16 (33.3)	6.17, 1, 0.013
	No	05 (31.2)	11 (68.8)	
Post-test counseling	Yes	36 (59.0)	25 (41.0)	Fisher's Exact p value-0.568

Most of the HIV Positive individuals 72 (97.3) anticipated that their wife would be upset when they disclose their status while only 02 (2.7) thought she will not be upset. The reason told by these 02 individuals was that 'she is uneducated and hence will not be able to understand the consequences'

On asking about the 'reason for such a negative response' 49 out of 72 (68.1) thought the reason as "her future was in jeopardy" followed by 11 (15.3) cases as "hiv is sexually transmitted disease". other less common reasons were "hiv is a killer disease for the individual" in 06 (8.3) cases, "individual may have infected his wife" in 04 (5.5) cases, "fear of negative response of others in community" in 01 (1.4) case and "can't say" in 01 (1.4) case (Figure 3).

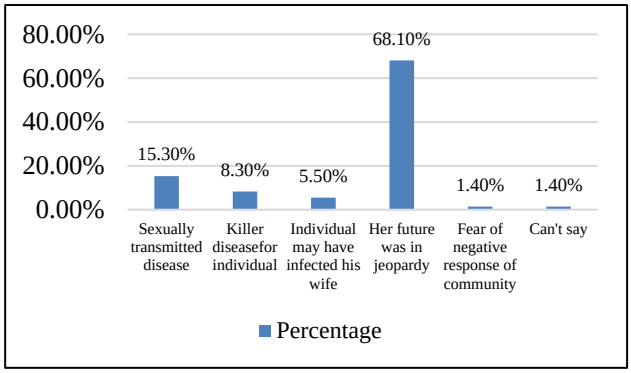

Figure 3: Most important reason for anticipated negative response of wife.

Most of the individuals 58 (90.6) reported 'feeling better' after conveying status to their spouse while very few 06 (9.4) reported either 'No change or felt worse than before' after conveying status.

Only 10% (08 out of 80) individuals faced problems due to their HIV status being known to any family member. Most of the individuals (90) did not face problems of any kind at home. A substantial number (26.1) of individuals reported that they faced problems due to their HIV positive status at workplace.

A remarkable number of individuals, 40 out of 53 (75.5) HIV positive Individuals who voluntarily disclosed their HIV status to spouse were always using condoms as compared to those who did not disclose their HIV status to spouse i.e. 03 out of 10 (30.0). Remaining 11 Individuals did not have sexual intercourse with their spouse since the diagnosis of HIV and hence were not considered for analysis. The association between disclosure of HIV status to spouse and regular Condom use since diagnosis of HIV was found to be highly significant with Fisher's Exact p-value - 0.008.

DISCUSSION

The overall proportion of Individuals who voluntarily disclosed their HIV status to spouse was 86.5% and only 13.5% individuals have not disclosed their status to spouse after they were given adequate time of 06 months for disclosure. Moreover, among those who voluntarily disclosed their HIV status to spouse, most of the individuals (92.2) disclosed within 6 months of diagnosis of HIV. In one study carried out in Kolkatta, India in 1994 disclosure rates of serostatus among married men to their partners was found to be 82.3%.[15] In another study carried out in South-West Ethiopia disclosure of HIV status to main sexual partners was reported to be 90.8%.[17]

11.9% of spouses came to know about individuals HIV status from other sources without the concurrence of the HIV positive individual. In 70% cases medical staff and in 30% cases workplace staff was responsible for it. A study carried out in Kolkata, India reported similar findings i.e. health professionals in 75% cases revealing the test results to family members. In all these situations disclosure occurred even though it was not desired by the subjects.[15]

Overall 46.7% of individuals voluntarily disclosed their HIV status to others excluding spouse and the most preferred for disclosing status were brothers/sisters (20.7) followed by colleagues (19.6) and parents (16.3). The least favoured for disclosure were other relatives (13.0) and Friends (13.0). In a study carried out in South-West Ethiopia disclosure of HIV status to relatives was 33.2% and to mother 14.9%. The prevalence of disclosure to a friend was 14.2 %, and to father was 9.1%.[17] The findings of our study were comparable to this study.

The proportion of subjects who voluntarily disclosed to spouse was higher in the older age group (> 30 years), group with less than 10 years of marriage, educated more than matric, group having rural background, individuals staying with wife at the time of testing and group given Post-test counseling. However, none of these were statistically significant. On the other hand, the relation between Individuals on ART and disclosure was found statistically significant as compared to those who were not on ART. Similar findings were observed when groups who disclosed in less than one month and those who disclosed in more than 1 month were compared for the same attributes except that in this case the group having more than 10 years of marriage had higher disclosure rates. However, none of these were also statistically significant. On the other hand, the relation between Individuals on ART and disclosure in less than 1 month was found to be statistically significant as compared to those who were not on ART.

In our study most of the individuals (97.3) anticipated negative response from their wife following disclosure. The reason commonly thought in 68.1% cases for such a response was “her future was in jeopardy” followed by “HIV is sexually transmitted disease” in 15.3% cases, “HIV is a killer disease for the individual’ in 8.3% cases and “individual may have infected his wife” in 5.5% cases. However, the actual response in most of the cases (90.6) was ‘as expected by individual’ or ‘better than expected’ and in only 9.4% cases it was worse than expected. Only in one case the outcome was severe in that the spouse deserted the individual after disclosure. Most of the respondents (90.6) felt better after conveying result to spouse and only one individual reported feeling worse. Most of the studies worldwide and in India have reported similar findings. Studies from both developing and developed country settings reveal that HIV status disclosure to sexual partners in most of the cases was associated with positive outcomes. Positive outcomes included increased support, acceptance, and kindness.[19-21] One of the studies also found that less than 5% of women reported any negative reactions following disclosure.[20] Disclosure was associated with less anxiety, fewer symptoms of depression, and increased social support.[22,23]

Voluntary disclosure of HIV status to spouse was found to be significantly associated to regular condom use. The individuals who voluntarily disclosed their HIV status to spouse within one month were also found to be more likely to always use condom as compared to those individuals who disclosed their status in more than one month and this association was also found to be highly significant. This finding emphasizes the fact that voluntary disclosure is either a determinant or leads to Positive behaviours. Our findings were similar to a study carried out in Ethiopia where participants who disclosed their status used condom at recent sexual intercourse 6.3 times higher than those who did not disclose (OR, 6.3; 95% CI, 3.7-10.8) and 4.2 times more likely to use condom consistently (use condom always) since HIV diagnosis (OR, 4.2; 95%CI, 2.4 - 7.3).17 Similarly other studies also found association between disclosure and condom use.[19,24,25]

CONCLUSION

The present cross-sectional, descriptive hospital based study conducted on HIV positive patients has provided an insight into the current knowledge of disclosure of their sero-status to their spouses and others, factors affecting it and related problems faced by them. Knowledge of HIV transmission which is only a prelude to attempt at behaviour change needs to be far higher than that evident in the respondents. Urgent measures for health promotional activities are therefore required.

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