

Disclosure of HIV Status and Social Support Among People Living With HIV



Medical Science

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ABSTRACT

Context: HIV/AIDS stigma is acknowledged as a major barrier in the path of HIV prevention strategies. People living with HIV/AIDS (PLHAs) are afraid of disclosure of their HIV status and perceive themselves unworthy of getting support from others.

Objectives: The present study aimed to determine HIV disclosure status and social support perceived by PLHAs.

Materials and methods: A cross sectional study, using systematic random sampling was carried out on 322 people living with HIV/AIDS attending antiretroviral therapy (ART) centres in Lucknow. Disclosure of HIV status and perceived social support were assessed with the help of a predesigned and pretested semi structured questionnaire.

Result: PLHAs often disclosed their HIV status to family members including spouse, parents and siblings. All of the PLHAs in the study population had disclosed their HIV status to at least someone. Proportion of parents and children supporting PLHAs even after knowing HIV status was quite high (94.7%)

Conclusions: Disclosure decision is primarily based on identification of safe and confident situations for disclosure by PLHAs. Social support if provided could help in making a better environment thereby decreasing negative experiences and hopes perceived by PLHAs.

Introduction

HIV/AIDS related stigma is a complex concept that refers to prejudice, discounting, discrediting and discrimination directed at persons perceived to have AIDS or HIV, as well as their partners, friends, families and communities. [1] HIV/AIDS stigma is a problem throughout the world which adversely affects the health and well-being of the affected individual. The National AIDS Control Program (NACP) of India recognises AIDS stigma as a significant barrier towards efforts made for HIV prevention. Therefore stigma and discrimination is addressed as a guiding principle in NACP phase III for prevention and control of HIV. [2] Disclosure of HIV status is believed to be an important factor for enhancing self-care behaviours, psychological well-being, commitment to the treatment, and reducing risk of transmission among PLHAs. [3]The World Health Organisation (WHO) cites fear of stigma and discrimination as the main reason why people are reluctant to get tested and disclose their HIV status. [4] Disclosure of HIV status is a kind of decision. One of the major advantages of disclosure is social support, which if received from others play an essential role for effective coping with HIV. [5] Disclosure of HIV status to family members, relatives, friends, employer and co-workers is matter of concern among PLHAs and is a highly personal decision. [6]Apart from getting social support, disclosure has other important benefits like increased opportunities for HIV risk reduction as well as to plan for the future opportunities. While choosing to disclose their status, PLHAs has to negate fears of potential stigma and discrimination, the fear of being rejected, and for some, and the fear of violence. [7] Therefore PLHAs opt to keep their HIV status as a secret. Therefore the present study was conducted to determine HIV disclosure status and social support perceived by PLHAs.

Materials and methods

The present study was a hospital-based cross-sectional study at two ART centres of Lucknow (King George's Medical University and Ram Manohar Lohia Institute of Medical Sciences). A total 322 PLHAs aged ≥ 18 years, and who have been enrolled at the centre for at least six months were enrolled in study using systematic random sampling. On the days of data collection, all patients who were eligible for inclusion in the present study were interviewed in private after obtaining a written consent. This study was approved by the Institutional Ethics Committee of King George's Medical University. Data regarding bio-social

characteristics and disclosure of HIV status and perceived social support was collected using a predesigned and pre-tested semi structured questionnaire. Data was compiled and analysed using Microsoft Excel and was transferred on the pre- designed classified tables and analysed according to the aims and objectives.

Results

About half (47.5%) of the patients were in age-group 31-40 years followed by 21.4% in age-group 18-30 years. 74.5% belonged to Hindu religion followed by Muslim and others (23.9% and 1.6% respectively). About two-third were male and 63.4% were married. There was almost an equal distribution with respect to urban and rural residence (50% each). Nearly two-third (65.5%) of the patients belonged to family of average size ≤ 5 . Near about one-fourth (28.6%) of the patients were illiterate. About 65.2% were employed and majority of them were skilled/semiskilled workers. About 57 patients out of 322 were below poverty line and about two-third (64.6%) belonged to socio-economic status upper lower and below according to Modified B G Prasad socioeconomic scale 2013. There was no patient in the study population who had not disclosed their HIV status to anyone. About two-thirds of patients had disclosed about their HIV status to their spouse, parents and siblings. Even some (3.5%) of the patients has disclosed their HIV status to their employer and co-workers. All of the patients in the study population had disclosed their HIV status to their spouse, followed by siblings (64.5%) and parents (64.1%). Few (12.9%) disclosed about their HIV status to their employer and co-workers. [Table 1]

Out of 214 PLHAs who had disclosed their HIV status to their spouse, 4.5% didn't perceive themselves as getting support from their spouses. About one-tenth of the patients who disclosed their HIV status to their friends didn't received any sort of social support from them. Although the proportion of parents and children supporting PLHAs even after knowing HIV status was quite high (94.7%). However the proportion of in-laws supporting PLHAs after disclosure of HIV status was quite less (78.8%). [Table 2]

Discussion

The present study was conducted to determine the pattern of HIV-status disclosure and perceived social support among people living with HIV/AIDS. Similar to the previous studies, disclosure of HIV status was found to vary

with respect to the types of relationship viz. spouse, parents, children, friends etc. [8, 9, 10] The feeling of easiness, degree of closeness in terms of relation and understanding and self-perception of PLHAs towards others might be the reason for this variation. It also means that PLHAs trust their family members more than others. Zahra *et al*; opined that participants share their HIV status more with their family members who were considerably perceived as more supportive. [3] Therefore in the present study PLHAs disclosed their HIV-status more to their family members rather than friends and co-workers. More than ninety per cent of the spouses support their partner even after knowing their HIV status. This enlightens the role of spouse to be the most proximate person in enhancing the well-being of PLHAs and preventing them in indulging high risk sexual activities. Also the support of family members was found to be quite high which is a favourable finding of the study as the behaviour family members including parents, siblings and children could have both the positive and negative impact on the psychological well-being of the PLHAs. The results of the present study must be interpreted with regard to limitations, as the results relied totally on self-report with regards to disclosure of HIV-status to family, friend and others and perceived social support from them. Also causal inferences couldn't be drawn as study was cross-sectional.

Conclusions

It can be concluded that HIV disclosure status might be based on the barriers and needs, as perceived by PLHA, and varies according to specific types of relationships and social networks. Apart from that there is a need assist and counsel PLHA as well as their caregivers regarding positive benefits that can occur by disclosing of HIV-status.

Table 1: Distribution of patients attending ART centre on the basis of disclosure of HIV status to others

(N=322)

Disclosed to Whom	No.	Percentage
Spouse	214	68.4
Siblings	205	65.5
Parents	189	60.4
Children	133	42.5
In laws	108	34.5
Close friends	80	25.6
Employers and coworkers	11	3.5

*Multiple responses

Table 2: Distribution of patients attending ART centre on the basis of social support perceived by others

(N=322)

Variable	Total	Social support perceived	
		Yes	No
Spouse	214	20(93.4)	14 (6.5)
Friends	80	71(88.7)	9 (11.3)
Parents	189	179(94.7)	10 (5.3)
Siblings	205	192(93.6)	13 (6.3)
Children	133	126(94.7)	7 (5.3)
In laws	137	108(78.8)	29 (21.2)
Employer and coworkers	11	6(54.5)	5 (45.5)

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