ORIGINAL RESEARCH ARTICLE

Estimating HIV Disclosure and Its Impact on Social Relations: A Cross-Sectional Study in Gujarat, India

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ABSTRACT

Background: The disclosure of HIV-positive status can significantly impact social relationships. This study aimed to evaluate the prevalence of self-disclosure of HIV status and its effects on social relations among individuals living with HIV (PLHIV) in Gujarat, India.

Methods: Conducted from April to June 2021, this cross-sectional study involved 383 PLHIV attending a tertiary-care medical college hospital in Gujarat, India. The sample size was determined using Epi Info software version 7. Data collection utilized a structured questionnaire covering socio-demographic information, HIV disclosure status, and its impact on social relationships. Multiple logistic regression analysis identified predictors of non-disclosure of HIV status to spouses.

Results: Among the 383 participants, 83% disclosed their HIV status to their spouse, while disclosure rates to other social contacts varied. Post-disclosure, 7% reported strained or broken relationships with their spouses. Factors associated with non-disclosure to spouses included older age (adjusted odds ratio [aOR] 1.13, 95% confidence interval [CI] 1.07-1.20), female gender (aOR 6.00, 95% CI 1.81-19.88), lack of post-test counselling (aOR 3.29, 95% CI 1.01-10.70), and spouse being HIV-negative (aOR 3.60, 95% CI 1.27-10.25).

Conclusion: In conclusion, while a significant proportion of PLHIV disclosed their HIV status to spouses, a notable proportion experienced strained relationships post-disclosure. Addressing barriers to disclosure, especially among older individuals and females, and ensuring adequate post-test counselling, may facilitate open communication and support among PLHIV and their social networks.

Keywords: HIV, disclosure, social relations, PLHIV, cross-sectional study, India, spousal disclosure, post-test counselling

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INTRODUCTION

The global and national burden of human immunodeficiency virus (HIV) highlights the pressing need to comprehend disclosure patterns and their repercussions on social interactions. In 2022, the global tally of individuals living with HIV stood at 39 million, with 1.3 million new infections recorded.[1] Within India, the HIV landscape was significant, encompassing 2.5 million people living with HIV (PLHIV) and 0.7 million new infections.[2] The India HIV Estimation 2022 report indicated a national adult HIV prevalence of 0.20%, with a female prevalence of 0.11%.[2] Notably, Gujarat ranked eighth among states in terms of estimated prevalence, with 0.18% prevalence and 0.12 million burden.[2]

Despite a relatively high awareness of HIV status among affected individuals, comprehensive data on self-disclosure to social contacts remains scarce.[1,2] Studies have highlighted a tendency to disclose HIV-positive status to healthcare providers rather than caregivers, especially concerning infected children, revealing the intricate nature of disclosure dynamics.[3] Stigma, discrimination, and fear of family disruption have been identified as significant barriers to disclosure, particularly in Gujarat.[4]

Existing literature primarily focuses on spousal disclosure and its impact on offspring, with minimal exploration of broader social networks.[5-12] While acknowledging the importance of policies integrating family members and caregivers into prevention and treatment initiatives[5], the persistent link between HIV-related stigma and reduced disclosure opportunities remains concerning.[13] Despite the emphasis on spousal disclosure, research on predictors of non-disclosure to spouses, particularly among men, is lacking, leaving the broader implications on other social ties relatively unexplored.[14]

The current evidence gap necessitates a thorough investigation into disclosure to all social contacts among PLHIV and its ramifications on relationship dynamics. Understanding the intricacies of HIV disclosure and its influence on social bonds is paramount for tailored interventions to support PLHIV and their families. Notably, men exhibit significant delays in disclosing their HIV status to spouses.[15] This study aims to gauge the prevalence of self-disclosure of HIV-positive status and its impact on social relations, while identifying predictors associated with non-disclosure to spouses, thereby contributing to a deeper comprehension of HIV disclosure dynamics in Gujarat, India.

METHODOLOGY

Study design, period and setting: The study utilized a cross-sectional design and took place at a tertiary-care medical college hospital in Gujarat, India. Data collection occurred over three months, from April to June 2021. The medical college hospital provides support for vocational and economic enhancement, as well as counseling services for HIV-positive individuals, under the guidance of individuals living with HIV/AIDS.

Study population: The inclusion criteria encompassed all HIV-positive patients aged 18 years and above, who provided written informed consent to participate in the study. A sample size of 383 was calculated using Epi Info software version 7,[16] with an assumed prevalence of true self-disclosure of illness to spouses at 52%,[17] a 95% confidence interval, and 5% absolute precision.

Subject selection: The sampling frame comprised Persons Living with HIV/AIDS (PLHAs) who visited the hospital in January-March 2021. Using simple random sampling, individuals were selected from a line-listing of HIV-positive patients aged 18 years and above who visited the hospital during that period. Upon agreement to participate, interactions occurred at participants' residences, or the ART Centre of the hospital. Detailed information about the study, its objectives, and implications was provided, and informed written consent was obtained. Continuous efforts were made to ensure clarity and understanding of the study's aims and procedures, prioritizing participant autonomy and comprehension.

Data collection: Upon obtaining consent, participants received a questionnaire covering socio-demographic information, disclosure status, and the impact on social relationships. For illiterate patients, counsellors conducted interviews. The questionnaire underwent validation by five experts and pilot testing to refine it. Data collected during the pilot study were excluded from analysis to ensure integrity. This iterative process aimed to enhance validity and strengthen the study's findings.

Variables: The study identified two primary outcome variables: the proportion of patients disclosing their HIV status and the resulting impact on relationship dynamics, categorized as 'strained or broken' post-disclosure. Additionally, it explored the percentage of patients abstaining from disclosing to their spouse, alongside predictor variables including CD4 count, pre-test and post-test counseling status, family size, spouse's HIV status, duration since diagnosis, and depression levels assessed through the Beck Depression Inventory (BDI-II).[18] These predictors aimed to offer insight into the multifaceted determinants influencing disclosure behavior among PLHIV, contributing to the broader discourse on HIV disclosure dynamics and its social implications.

Socio-economic and occupation classification: Socio-economic and occupation classification parameters were meticulously defined to capture the socio-economic diversity within the study population accurately. Modified Prasad's classification was utilized to ascertain socio-economic status, incorporating the All-India Consumer Price Index for Industrial Workers (AICPI-IW) value for June 2012 for contextual relevance.(19,20) Occupational classifications fol-

lowed the National Classification of Occupations (2004) provided by the Directorate General of Employment & Training, ensuring standardized categorization of participants' occupations.[21]

Quality control: Quality control measures were implemented at every stage of the study to maintain data integrity and research validity. Comprehensive piloting of study procedures, including recruitment and data entry, was conducted to assess feasibility and identify procedural modifications. Data entry was meticulously performed using Epi Info software version 7,[16] with stringent data checks to mitigate errors and ensure accuracy. These meticulous quality control measures underscore the reliability and validity of the study findings, enhancing the credibility of the research outcomes.

Statistical analysis: The primary outcome variable, representing the percentage of HIV status disclosure, was presented in percentages to elucidate disclosure patterns among participants. Multiple logistic regression (MLR) analysis, employing the backward likelihood ratio method, was conducted to identify independent predictors influencing non-disclosure of HIV-positive status to spouses, with statistical significance set at p-value <0.05. Data analysis was performed using the Statistical Package for Social Sciences (SPSS) version 23, ensuring thorough statistical exploration.[22]

Ethical considerations: Ethical considerations were rigorously followed throughout the study. Informed written consent was obtained from all participants, ensuring their voluntary participation and comprehension of the study's objectives. Approval was obtained from the Institutional Ethics Committee (IEC) of a medical college of Gujarat, affirming compliance with ethical standards and guidelines. Confidentiality of all collected information was strictly maintained, with patient identities anonymized and represented solely by study identification numbers in the case record forms.

RESULTS

Out of the initial sample, 19 participants declined participation, resulting in a 5% non-response rate. However, the sample size of 383 was achieved by including these non-respondents. Among the enrolled 383 patients, the mean age was 40 years, with a median of 39 years, ranging from 19 to 65 years (Table 1). The majority (74%) were male, 13% were illiterate, 75% were currently married, 21% were unemployed, and 37% belonged to socioeconomic class IV.

Among the 383 study participants, 83% disclosed their HIV status to their spouse, while 56% disclosed it to their parents, and half to their in-laws (Table 2). Additionally, 43% disclosed their HIV status to their children. Notably, 77% of PLHIV chose not to disclose their status to co-workers or their employer.

Table 1: Socio-demographic characteristics of the People Living with HIV (n=383)

Socio-demographic characteristics	Participants(%)
Age of patient in years	
<40 years	193 (51)
≥40 years	190 (49)
Gender	
Male	285 (74)
Female	97 (25)
Transgender	1 (0)
Educational status	
Illiterate	48 (13)
Just literate	76 (20)
Primary (5th Std.)	88 (23)
Middle (8th Std.)	60 (16)
Secondary (10th Std.)	63 (16)
Higher secondary (12th Std.)	30 (8)
Graduate and above	18 (5)
Literacy status	
Illiterate	48 (13)
Literate	335 (87)
Marital status	
Currently married	287 (75)
Widow	27 (7)
Separated	13 (3)
Unmarried	23 (6)
Widower	20 (5)
Divorcee	13 (3)
Occupational status	
Professionals	3 (1)
Technicians and associate professionals	7 (2)
Service workers and shop & market sales workers	37 (10)
Skilled agricultural and fishery workers	16 (4)
Craft & related trade workers	132 (34)
Plant & machine operators and assemblers	53 (14)
Elementary occupations	55 (14)
Workers not classified by any occupations	80 (21)
Modified Prasad's class	
I	21 (5)
II	62 (16)
III	113 (30)
IV	141 (37)
V	46 (12)

After disclosure, about 7% faced strained relationships with both spouse and in-laws (Table 3). Conversely, only 2% experienced strained relationships after disclosing to parents. Disclosing to children mostly resulted in improved or unchanged relationships. Approximately 1% experienced strained relationships after disclosing to co-workers, and 4% after disclosing to employers.

Following backward step-wise Likelihood Ratio in multiple logistic regression, the model concluded at step 6, excluding socio-economic class, CD4 count, family members, years since diagnosis, and absence of pre-test counselling (Table 4).

Table 2: Disclosure status of the People Living with HIV (n=383)

Disclosure status	Frequency (%)
Spouse	
Disclosed	318 (83)
Not disclosed	65 (17)
Parents	
Disclosed	213 (56)
Not disclosed	170 (44)
In-laws	
Disclosed	189 (49)
Not disclosed	194 (51)
Siblings	
Disclosed	258 (67)
Not disclosed	125 (33)
Friends	
Disclosed	159 (42)
Not disclosed	224 (58)
Children	
Disclosed	165 (43)
Not disclosed	218 (57)
Neighbour	
Disclosed	107 (28)
Not disclosed	276 (72)
Co-workers	
Disclosed	88 (23)
Not disclosed	295 (77)
Employer	
Disclosed	83 (22)
Not disclosed	300 (78)

Table 3: Effect of disclosure of HIV status by the patients on relationships (n=383)

Relationship after status disclosure	Frequency (%)
Spouse	
Strained or broken	23 (7)
Improved or same as before	295 (93)
Parents	
Strained or broken	5 (2)
Improved or same as before	208 (98)
In-laws	
Strained or broken	13 (7)
Improved or same as before	176 (93)
Siblings	
Strained or broken	16 (6)
Improved or same as before	240 (94)
Friends	
Strained or broken	2 (1)
Improved or same as before	157 (99)
Children	
Strained or broken	0 (0)
Improved or same as before	165 (100)
Neighbours	
Strained or broken	8 (7)
Improved or same as before	99 (93)
Coworkers	
Strained or broken	1 (1)
Improved or same as before	87 (99)
Employer	
Strained or broken	3 (4)
Improved or same as before	80 (96)

The finalized model revealed significant associations: each year increase in patient age correlated with 13% higher odds of non-disclosure ($p<0.001$); illiterate patients displayed markedly higher odds of non-disclosure compared to literate counterparts ($p=0.014$); females exhibited 6 times higher odds of non-disclosure than males ($p=0.001$); patients lacking post-test counselling were 3 times more inclined to withhold disclosure ($p=0.048$); furthermore, patients with HIV-negative spouses had 3.6 times higher odds of non-disclosure than those with HIV-positive spouses ($p=0.016$).

DISCUSSION

The study explored HIV status disclosure prevalence among PLHIV in Gujarat, India, indicating widespread disclosure to spouses but limited disclosure to other social circles. Post-disclosure, strained relationships with spouses and in-laws were common, contrasting with improved or unchanged relationships with children. These insights shed light on the complex dynamics of HIV disclosure and its social repercussions within and beyond familial contexts.

The observed patterns of HIV status disclosure and its impact on social relationships stem from diverse factors. Older patients' reluctance to disclose may relate to differing attitudes towards HIV, stigma, and fear of social consequences across generations. Illiterate patients heightened non-disclosure rates underscore the pivotal role of education in fostering HIV communication. Gender disparities in disclosure may reflect societal norms and power dynamics, with women facing more barriers. Moreover, the absence of post-test counselling underscores the vital role of support services in encouraging disclosure and combating stigma.

The study's implications for HIV care and support services are significant. Factors linked to non-disclosure can inform interventions promoting communication and reducing stigma. Integrating counselling in HIV care can facilitate disclosure discussions and offer emotional support. Raising awareness about disclosure benefits and dispelling misconceptions can foster supportive environments. Overall, these findings underscore the importance of holistic HIV care, prioritizing the psychosocial welfare of PLHIV and their families.

In line with previous research conducted in Ethiopia (76%), Iran (60%), South India (80%), and Central India (85%), our study revealed a high prevalence of disclosure to spouses (83%) among PLHIV, with only a study in Bengaluru reporting a lower percentage of 41%.[6,14,23-25] Moreover, consistent with existing literature, our findings underscored the significance of factors such as age, education level, gender, and the availability of counseling services as influential determinants of disclosure behavior.[6,14,23,26] These results underscore the necessity for intensified awareness campaigns and expanded HIV-related counseling services, particularly with gender-specific interventions.

Table 4: Adjusted Odds Ratio of significant predictor variables predicting non-disclosure of HIV status to spouse by multiple logistic regression* (n=328)

Variables	Beta coefficient	S.E (mean)	Wald	Adjusted OR	95% CI	P-value
Age in years	0.12	0.029	17.8	1.13	1.07-1.2	<0.001
Education						
Illiterate - reference	-	-	14.04	-	-	0.029
Just literate	-2.4	0.996	6.01	0.087	0.012-0.613	0.014
Primary 5th std.	-1.24	0.732	2.9	0.29	0.07-1.22	0.091
Middle 8th std.	-2.24	0.91	6.1	0.11	0.02-0.63	0.014
Secondary 10th std.	-0.51	0.74	0.48	0.6	0.14-2.54	0.487
Higher secondary 12th std.	-0.39	0.83	0.22	0.68	0.13-3.5	0.638
Graduate and above	0.38	0.79	0.24	1.47	0.31-6.9	0.628
Male gender	-1.86	0.55	11.6	0.16	0.05-0.45	0.001
Depression score	0.04	0.02	3.16	1.04	0.99-1.09	0.076
No post-test counselling	1.19	0.6	3.92	3.29	1.01-10.7	0.048
Spouse HIV negative	-1.28	0.53	5.8	3.6	1.27-10.3	0.016
Constant	-5.64	1.25	20.35	.006	-	<0.001

*Omnibus test of model coefficients p-value <0.001; Hosmer Lemeshow test p-value=0.117; Nagelkerke R^2 value=0.327; Classification accuracy 92.7% (22.2% for 'non-disclosure to spouse' and 99% for 'disclosure to spouse').

Our study uncovered strained or broken relationships with spouses and improved relationships with children post-disclosure. Interestingly, our findings contradicted a previous study's hypothesis regarding the predictive effect of relationship quality on disclosure outcomes.[27] Instead, our results suggest an interaction between the fear of family breakdown, acting as a deterrent to HIV disclosure, consistent with insights from other studies.[24,25,28-31] Family group psychotherapy has been identified as a useful intervention for HIV disclosures to the family.[32] In summary, our study illuminates the complex dynamics of HIV disclosure and its impact on family relationships, emphasizing the necessity for tailored interventions to address associated challenges.

While this study offers valuable insights into HIV disclosure among PLHIV in Gujarat, it's vital to acknowledge inherent limitations associated with its cross-sectional design. Concerns regarding potential recall bias and the inability to establish causality are noteworthy. Additionally, the study's failure to explore underlying reasons for non-disclosure of HIV status presents a notable gap. Addressing these factors could inform targeted interventions to support PLHIV in disclosure decisions. Nevertheless, the study demonstrates strengths, including a robust methodology, comprehensive questionnaires, and adherence to ethical standards.

Looking ahead, future research endeavours could benefit from employing longitudinal designs and incorporating objective measures of disclosure behaviour. Longitudinal studies would enable the examination of changes in disclosure patterns over time, offering deeper insights into the dynamics of HIV disclosure and its impact on social relationships among PLHIV. Moreover, incorporating objective measures, such as partner reports or medical records, could mitigate the potential biases associated with self-reported data, further strengthening the validity and reliability of research findings.

Conclusion

In conclusion, our study in Gujarat, India, underscores the intricate relationship between HIV disclosure and social dynamics among PLHIV. It highlights the need for tailored interventions to aid individuals in navigating disclosure and alleviating negative relationship repercussions. Implementing counseling services focusing on communication skills, stigma reduction, and relationship management strategies is imperative, complemented by healthcare providers fostering open and supportive environments for disclosure discussions. Community-driven initiatives promoting empathy and education, dispelling HIV-related myths, and advocating for accessible counseling services through healthcare policies are pivotal in combating discrimination, strengthening support networks, and empowering individuals to make informed decisions about HIV disclosure. These measures collectively contribute to fostering a more inclusive and supportive societal environment.

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