

“My Life is Spoiled Because of Him...” A Qualitative Study of Human Immunodeficiency Virus Disclosure and Male Involvement in Prevention of Mother-to-Child Transmission Program

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Abstract

Background: India has the third largest human immunodeficiency virus (HIV) epidemic in the world, with 15,000 newborns infected every year. Prevention of mother-to-child transmission (PMTCT) services can eliminate new HIV infections. Nondisclosure of positive HIV status and nonoptimal uptake of PMTCT are related. Therefore, understanding different aspects of HIV disclosure are necessary for program managers and careproviders for prevention and support. **Objective:** The present research explores HIV disclosure narratives, the family’s perspective, and theoretical framework in the context of PMTCT. **Methods:** A qualitative study was conducted among 31 (16 mothers and 15 fathers) utilizers of PMTCT at an urban antiretroviral therapy center. A semi-structured in-depth interview guide based on disclosure process model (DPM) was used to explore HIV disclosure goals and outcomes by both members of parental dyad. The recorded interviews were transcribed verbatim, translated into English, and analyzed with Atlas.ti software. Directed content analysis was used to code data according to “*a priori*” and emerging themes. Demographic data were analyzed using descriptive statistics. **Results:** Limited disclosure is a necessity for pregnant women and their male partners for approach coping with HIV diagnosis and pursuing positive support for PMTCT adherence. Interpersonal, society, and community contextual outcomes affect the care uptake and future likelihood of disclosure. **Conclusions:** DPM suggestions from the present study can be used to facilitate a goal-directed process that allows parents/PLWHA to selectively disclose their HIV status to family members and acquaintances for obtaining maximum support to eliminate newborn HIV infections while minimizing distress, stigma, and discrimination.

Keywords: Disclosure process model, elimination of mother-to-child transmission, family, human immunodeficiency virus disclosure, male involvement, prevention of mother-to-child transmission, qualitative

INTRODUCTION

India has the third largest human immunodeficiency virus (HIV) epidemic in the world with 15,000 newborns infected annually.^[1,2] HIV may impact the growth of both exposed and infected infants;^[3,4] however, if mothers are able to obtain and adhere to prevention of mother-to-child transmission (PMTCT) services as recommended by the WHO and National AIDS Control Organization (NACO), elimination of vertical transmission (EMTCT) can be achieved.^[5-7]

Nondisclosure of HIV and nonoptimal uptake of PMTCT are related.^[5,6,8-10] Systematic reviews find the lowest HIV

disclosure rates among antenatal women.^[6,8,9] To date, most research among PMTCT populations has been conducted with mothers and fathers’ involvement in HIV disclosure has been rarely studied,^[6,9,11] though family members notably

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male partners/fathers^[12] play a substantial role in improving HIV-related outcomes.^[9,13,14] Moreover, most qualitative studies have been conducted in Africa and developed countries^[6,8,9] and may not be applicable to cultures such as India where families and husbands play fundamental roles in approval and support of women's decisions.^[15]

The present study details these less explored domains of HIV disclosure in Indian PMTCT from the perspective of both members of parental dyads, with the help of a conceptual theoretical framework-disclosure process model (DPM). We anticipate that understanding the highly complex process of revealing a concealable identity, like HIV, will help program managers and health-care providers formulate strategies to strengthen PMTCT programs, with special emphasis on obtaining care and support through disclosure of HIV status.

METHODS

Study design and settings: This was a qualitative study conducted at an antiretroviral therapy (ART) center of an urban tertiary referral care institute for >10 million people in Western India. The ART Centre provides diagnosis, treatment, care, and support for approximately 50% of PLWHA residing in neighboring rural or urban locations.

Participants

Men, whose wives/or partners were HIV-seropositive as well as HIV-positive women who had availed any of the PMTCT services, were included. All participants were currently attending the ART center after the birth of their baby. Other inclusion criteria were: (1) ≥ 18 years, (2) able to speak Hindi/Gujarati, (3) able to give informed consent, (4) willing to participate, and (5) PMTCT utilizer within the last 3 years.

Procedure

This research was approved by the Institutional Ethics Committee and Review Board. Purposive sampling was used to recruit the study participants.^[16] Two members of the study team who are practicing health-care providers at the ART center described the study to potential participants using a participant information sheet. Those who agreed to participate were assessed for eligibility and requested to provide written informed consent.

Study data collection instruments were a semi-structured in-depth interview guide based on the DPM and a demographics standardized questionnaire. The DPM constructs are antecedent goals, outcomes, and a feedback loop. The model specifies that disclosure begins with a decision-making process, in which approach and avoidance antecedent motivations affect disclosure likelihood and subsequent outcomes. Approach goals focus on a rewarding or desired end state and are associated with positive stimuli, positive affect, and approach-focused coping strategies. On the other hand, avoidance goals focus on avoiding a punishing or undesired end state and are associated with negative stimuli, negative affect, and avoidance-focused coping strategies. Disclosure

can affect individual, dyadic, and social contextual outcomes. Finally, the DPM suggests a single disclosure event can affect subsequent disclosure trajectories through a feedback loop.^[17]

The interview guide was developed in English, translated into local languages (Hindi and Gujarati) and piloted.

Each interview was conducted in a private room within the ART center by one member of the investigative team trained in qualitative research methodology. The average interview lasted 25 min (range 15–30 min). We performed 31 interviews to achieve theoretical saturation of themes (DPM constructs of interest).

Data processing and analysis

The confidentiality of information provided by participants was maintained throughout the study. The recorded interviews were transcribed verbatim and translated into English. A directed content Analysis method^[18] was used to code interview data using an “a priori” list of codes based on DPM themes.^[17] was used to code interview data using an “a priori” list of codes based on DPM themes.^[17] Two coauthors independently coded four interviews each and then met to discuss differences in coding to reach consensus. A prediscussion 86% agreement was found among the two coders. Qualitative analysis and demographic data was managed by Atlas.ti version 7 (qualitative data analysis software developed by Scientific Software Development GmbH) and Microsoft Excel respectively. The SRQR standards for reporting qualitative research were followed.^[19]

RESULTS

Thirty-one participants (16 mothers and 15 fathers), including six couples, completed demographic surveys and interviews [Table 1]. Mean age of mothers was 26 (range 21–30) and fathers was 34.4 (28–43) years.

Antecedent goals

Pursuing positive outcomes and approach coping

In this study, all parents had chosen to disclose their HIV status to sexual partners and selected family members or friends as a form of approach coping with the purpose of obtaining acceptance and support (i.e., emotional, financial, physical). Women confided in their mother, sibling, or someone who was educated and had knowledge of health and illness. Men considered disclosure to his partner's relatives essential for getting support needed during pregnancy and childbirth [Figure 1 and Table 2].

In certain situations, the person who went with the participant to obtain initial HIV testing results, and thus learned that the participant was HIV-positive at the same time as the participant, became a close confidante later on:

My father was with me when I got my first report for the first time. My brother has also known since then (father).

Preventing negative outcomes and avoidance coping

Participants agreed unanimously that it is essential to conceal

Table 1: Sociodemographic characteristics of mothers (16) and fathers (15)

Characteristic	Mother (n=16)	Mothers % out of 16	Father (n=15)	Father % out of 15	Total (n=31)	Total (% out of 31)
Marital status						
Married	13	81.2	15	100	28	90.3
Separated or divorced	2	12.5	0	0	2	6.5
Widow or widower	1	6.3	0	0	1	3.2
Religion						
Hindu	13	81.3	15	100	28	90.3
Muslim	3	18.7	0	0	3	9.7
Residence						
Suburban	9	56.3	8	53.4	17	54.8
City	5	31.2	5	33.3	10	32.3
Rural and tribal	2	12.5	2	13.3	4	12.9
Occupation						
Unemployed	0	0	1	6.6	1	3.3
Unskilled worker	2	12.5	7	46.7	9	29
Skilled worker	2	12.5	7	46.7	9	29
Homemaker	12	75	0	0	12	38.7
Monthly income of couple in Rupees (INR)						
0-5000	5	31.3	1	6.6	6	19.4
5001-10,000	8	50	8	53.4	16	51.6
10,001-15,000	2	12.5	4	26.7	6	19.4
15,001-25,000	1	6.2	2	13.3	3	9.6

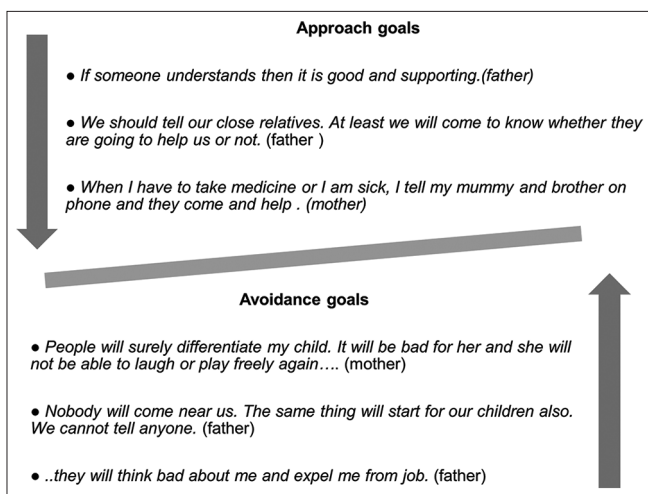


Figure 1: Antecedent goals of human immunodeficiency virus disclosure

their HIV-positive status to avoid criticism, judgment, discrimination, and ostracization in society and at work to prevent loss of wages [Figure 1].

Outcomes of human immunodeficiency virus status disclosure

At the interpersonal level, the majority of participants stated that they received positive encouragement from family or close friends to start and adhere to the PMTCT services. Many women found support from their husbands, especially if the man was diagnosed with HIV before the woman. These women felt that their husbands had been responsible for transmitting the HIV infection to their family. As a result, the men were

more caring and encouraged women to utilize PMTCT to prevent the baby from acquiring HIV too. Some participants further stated that they, as a couple, were responsible for solving problems on their own [Figure 2 and Table 2], while some blamed their partner for infecting them.

My husband behaves well and uses that which is to be used while relation... (nirodh-condoms)... he is never bad because he has got that too (HIV). We stay together. My life is spoiled because of him (mother).

Women preferred not to confide in their “in-laws” for fear of social distancing and rejection. In one case, an HIV-negative father looked after his HIV-positive wife and child [Figure 2].

Institutional or organizational outcomes

The support from physicians and health-care staff was considered crucial to managing HIV/AIDS. Fathers and mothers unanimously expressed a favorable view of the government health-care center, but they also did not want workers to visit them at home for fear of inadvertent disclosure [Figure 2].

Social or community contextual outcomes

Participants fears of social ostracization were realistic as some reported major changes in their lives and routine following disclosure of their HIV status.

My brother-in-law's wife's distant relatives heard and told many other people. They said that they will also get it. Therefore, I had to change homes (father).

Participants indicated that HIV is viewed by others as a disease of “morally lax” people and took extreme measures to conceal their HIV status, including not seeking medical assistance for the delivery of their child which later led to the death of the child [Figure 2].

Finally, some participants expressed regret for disclosing their HIV status to others.

It was a mistake to tell. If we would not have told it would have been better (mother).

Involuntary disclosure

In addition to constructs from the DPM, additional themes emerged. Some participants HIV status was disclosed during hospitalization events, such as long illnesses, deaths, pregnancy checkup, and childbirth.

My husband was admitted with sickness and vomiting. So my jeth (elder brother-in-law) was discussing... (mother).

My saas (mother-in-law) was there at the time of delivery; everyone knows (mother).

Sometimes, the HIV testing was performed at a private clinic where the testing report was given to a relative who further told many people [Figure 2].

DISCUSSION

The study findings provide evidence for the DPM theory when PLWHA are able to control the disclosure process through cognitive processing with development of approach/avoidance goals, making the decision to disclose, selecting a confidante, and performing the disclosure resulting in long-term outcomes and feedback loop.^[17] However, our

study also indicates that controlling the disclosure process may be difficult, as many times involuntary disclosure without permission occurred during initial diagnosis, severe illnesses, or other private (nongovernment) hospitalization episodes. Inadvertent disclosure disrupting normal life and repercussions occur more commonly in private medical sector in India.^[9,20] [Table 2] Therefore, developing and implementing policies for maintaining confidentiality of test results in Indian nongovernment settings is critical.

The authors observed the challenges that pregnant women and their male partners face when they learn about their positive HIV status for the first time during pregnancy. Frequently, the mothers reported that instead of sharing responsibility to prevent the unborn child from being infected with HIV, the father’s family, and often the fathers themselves, blamed the expectant mother. This burden is significantly more challenging for women in the Indian context as many live in their husband or partner’s multigenerational household. Fear of negative outcomes may lead women to hide their HIV-positive identity,^[6,11] which results in lost opportunities for the prevention of new HIV infections and the ability of these parents to access available care and support.^[6] On the other hand, some women felt that their male partners were demonstrating a caring attitude because their partners had infected them with HIV.

There is a need for a greater focus on assisting couples with the disclosure process during HIV counseling to enable the couple to obtain^[14] required support to initiate and adhere to PMTCT services. To do this, counseling needs to take into account whether a woman got her positive serostatus report before the testing of her husband/male partner and whether couple lives in a joint family household. If family members

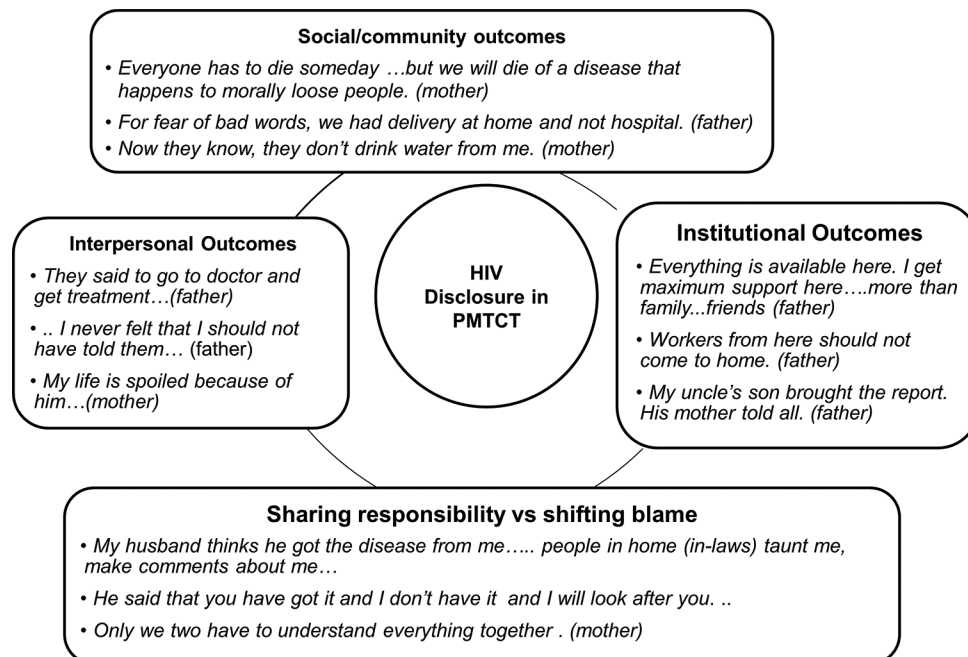


Figure 2: Outcomes of human immunodeficiency virus disclosure in prevention of mother-to-child transmission

Table 2: Thematic presentation of pregnant women and their male partners' goals and outcomes of human immunodeficiency virus disclosure in prevention of mother-to-child transmission

Main themes (DPM) construct	Sub-themes (codes)	Fathers	Mothers
Antecedent approach-focused goal	Approach coping Pursue positive outcomes	All disclosed to a selected close confidante	All except two mothers disclosed to their mother and/or brother
Antecedent avoidance-focused goal	Avoidance coping Prevent negative outcome	Better not to tell; stigma; expulsion from work	Avoid disclosure to in-laws; discrimination of child
Outcomes	Interpersonal	Woman's relatives and friends helped with treatment and care	Manage situation with support of husband
	Community and social contextual	Change homes, workplace, or locality	Considered to happen through a "bad" behavior or "bad" husband
	Organizational	Good behavior, attitude, and facilities	Approachable and accessible services and providers
Emerging theme involuntary disclosure	Private institution/indiscretion by care providers or relatives	Hospitalization episodes (death or illness)	Routine antenatal testing at private setups

DPM: Disclosure Process Model

accompany the couple to the hospital and become aware of at least one member's HIV status, then it should be explained that it is unclear who was infected with HIV first and that it would be beneficial for the family to maintain the confidentiality of this information.

At the interpersonal level, all participants interviewed had disclosed their positive HIV serostatus to their partners and at least one other person to cope with their diagnosis and avail optimal uptake of PMTCT services. Our study confirms that partner involvement and "family-centric" approach is the key to HIV disclosure in context of Indian PMTCT.^[5,6] Participants preferred and perceived that the mother and siblings of the pregnant woman/wife would be more empathetic and nonjudgmental [Figure 1 and Table 2]. Obermeyer's review of 231 studies also suggests that PLWHA generally have at least one confidante to gather social support.^[6,9,14]

At the social and community contextual levels, almost all parents experienced negative outcomes of disclosing their HIV status at some point in their lives, which reduced the likelihood that they would further disclose their HIV status to others [Figure 2 and Table 2]. The participants who received this negative feedback were blamed for being "bad." They also believed that HIV stigma and discrimination in society would affect their children or force them to move from their homes or even the area in which they resided, which was observed by other studies also.^[9] These findings suggest that there is a critical need for HIV awareness programs among the general population in India to normalize the disease and decrease widespread stigma. Similar to another study, the treatment, care, and support services provided by the public healthcare center made the study participants feel hopeful that they would be able to tolerate the difficulty of living with HIV.^[11]

Although this may be the first Indian study to explore in-depth disclosure narratives and extended family involvement using a conceptual framework in PMTCT, it is not without limitations. The findings may not be generalizable outside the settings of PMTCT/ART, to families not receiving PMTCT services,

or to families being treated in other locations globally. This study focuses on the past and anticipated experiences and is, therefore, amenable to recall bias.

CONCLUSIONS

This study provides comprehensive evidence that pregnant women and male partners need support from acquaintances and family members to cope with their HIV diagnosis and for initiation and adherence to PMTCT. Using suggestions from the DPM framework in context of PMTCT and EMTCT, parents/PLWHA should be encouraged to use a goal-directed process that allows them to selectively disclose their status to obtain maximum care and support while minimizing distress, stigma, and discrimination.

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Conflicts of interest

There are no conflicts of interest.

REFERENCES

1. National AIDS Control Organization and National Institute of Medical Statistics ICMR. India HIV Estimations 2015. Technical Report.

- New Delhi: Ministry of Health and Family Welfare, Government of India; 2016.
2. Joint United Nations Program on HIV/AIDS (UNAIDS). Global Factsheets 2017. HIV/AIDS Estimates; 2018. Available from: <http://aidsinfo.unaids.org/>. [Last accessed on 2018 Aug 10].
 3. Sangeeta T, Anjali M, Silky M, Kosambiya JK, Shah VB. Looking beyond prevention of parent to child transmission: Impact of maternal factors on growth of HIV-exposed uninfected infant. *Indian J Sex Transm Dis AIDS* 2014;35:109-13.
 4. World Health Organization. Technical Consultation on the Elimination of Mother-to-Child Transmission of HIV: Final Meeting Report. Geneva, Switzerland: World Health Organization; 2011.
 5. National AIDS Control Organization. National Guidelines for Prevention of Parent-to-Child Transmission of HIV. Department of AIDS Control, NACO, Ministry of Health and Family Welfare, Government of India; 2013.
 6. Medley A, Garcia-Moreno C, McGill S, Maman S. Rates, barriers and outcomes of HIV serostatus disclosure among women in developing countries: Implications for prevention of mother-to-child transmission programmes. *Bull World Health Organ* 2004;82:299-307.
 7. Jain KK, Mahajan RK, Shevkani M, Kumar P. Early infant diagnosis: A new tool of HIV diagnosis in children. *Indian J Community Med* 2011;36:139-42.
 8. Tam M, Amzel A, Phelps BR. Disclosure of HIV serostatus among pregnant and postpartum women in Sub-Saharan Africa: A systematic review. *AIDS Care* 2015;27:436-50.
 9. Obermeyer CM, Baijal P, Pegurri E. Facilitating HIV disclosure across diverse settings: A review. *Am J Public Health* 2011;101:1011-23.
 10. Jasseron C, Mandelbrot L, Dollfus C, Trocmé N, Tubiana R, Teglas JP, *et al.* Non-disclosure of a pregnant woman's HIV status to her partner is associated with non-optimal prevention of mother-to-child transmission. *AIDS Behav* 2013;17:488-97.
 11. Colombini M, James C, Ndwa C, Integra team, Mayhew SH. The risks of partner violence following HIV status disclosure, and health service responses: Narratives of women attending reproductive health services in Kenya. *J Int AIDS Soc* 2016;19:20766.
 12. Morfaw F, Mbuagbaw L, Thabane L, Rodrigues C, Wunderlich AP, Nana P, *et al.* Male involvement in prevention programs of mother to child transmission of HIV: A systematic review to identify barriers and facilitators. *Syst Rev* 2013;2:5.
 13. Myer L, Abrams EJ, Zhang Y, Duong J, El-Sadr WM, Carter RJ, *et al.* Family matters: Co-enrollment of family members into care is associated with improved outcomes for HIV-infected women initiating antiretroviral therapy. *J Acquir Immune Defic Syndr* 2014;67 Suppl 4:S243-9.
 14. Maman S, van Rooyen H, Groves AK. HIV status disclosure to families for social support in South Africa (NIMH project accept/HPTN 043). *AIDS Care* 2014;26:226-32.
 15. Patel SV, Patel SN, Baxi RK, Golin CE, Mehta M, Shringarpure K, *et al.* HIV serostatus disclosure: Experiences and perceptions of people living with HIV/AIDS and their service providers in Gujarat, India. *Ind Psychiatry J* 2012;21:130-6.
 16. Barbour RS. Checklists for improving rigour in qualitative research: A case of the tail wagging the dog? *BMJ* 2001;322:1115-7.
 17. Chaudoir SR, Fisher JD. The disclosure processes model: Understanding disclosure decision making and postdisclosure outcomes among people living with a concealable stigmatized identity. *Psychol Bull* 2010;136:236-56.
 18. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res* 2005;15:1277-88.
 19. O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: A synthesis of recommendations. *Acad Med* 2014;89:1245-51.
 20. Madhivanan P, Krupp K, Kulkarni V, Kulkarni S, Vaidya N, Shaheen R, *et al.* HIV testing among pregnant women living with HIV in India: Are private healthcare providers routinely violating women's human rights? *BMC Int Health Hum Rights* 2014;14:7.