

Full Length Research Paper

Disclosure of parental HIV status: Are parents telling their children and what are some factors influencing disclosure- A study from South India

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In the era of accessible antiretroviral treatment where HIV becomes a chronic disease, disclosure of parental HIV status to children is fraught with challenges. This study seeks to understand if parents disclose their HIV status to their children, and gain insight into some factors that influence disclosure. This is a cross sectional descriptive study on 115 of 136 HIV positive patients attending the outpatient clinic of the National Institute for Research in Tuberculosis (NIRT) situated in Chennai, South India. Disclosure was reported by twenty eight respondents (24%) of the respondents with 11(39%) who reported that it was done by them, the rest being unplanned or done by health providers. The most significant variables which influenced disclosure were age of the parents, (Adjusted OR = 14.7 C.I (3.2, 68), p-value: 0.001), divorced /widowed (Adjusted OR = 4.8, C.I (1.1, 22.1), p-value: 0.041) and having children ≥ 15 years (Adjusted OR = 3.1, C.I (1.1, 15.6), p-value: 0.043). It was also found that disclosure was more likely when both parents were positive. ($\chi^2 = 7.481, p < .05$). The most repeated reasons for disclosure were to protect their children from risky behavior and to take care of them when ill. Findings point to low rates of disclosure to children among parents living with HIV and complexities around disclosure. Parents require disclosure support services and health care providers need to be sensitized to include these services in HIV intervention programs.

Key words: Disclosure, Parents, HIV Status, children, Challenges.

INTRODUCTION

It is estimated that in India there are 2.3 million people infected with HIV, with 83 percent in age group 15-49 years (NACO 2011-12). While there are no reliable estimates of 'affected' children in the country, a UNGASS (United Nations General Assembly Special Session 2010) report summarizes that India possibly has 7,000,000 children with HIV-positive parents. With the recent rapid scale up of NACO's antiretroviral therapy (ART) programs across India, approximately 3.84 lakh people living with HIV (PLHA) including 22,837 children living with HIV or are currently receiving free ART in 292 public sectors ART centers. The free access to ART is decreasing mortality and morbidity in India (NACO 2009-10).

As HIV therefore becomes more of a chronic disease HIV positive parents are more likely to raise their children for many years, and disclosure of parental HIV status to children has become an increasingly significant issue (Mellins et al., 2002). Disclosure of parental HIV status to children has been shown to affect the well-being of children, parents, and family positively (Qiao et al., 2011). For example, disclosure is an important first step in gaining HIV-specific social support (Zea et al. 2005) and facilitate adherence to antiretroviral (ARV) medications (Spire et al., 2008) Despite these potential positive outcomes, disclosure also carries important risks. When information is shared with unaccepting individuals, it renders people living with HIV/AIDS vulnerable to stigmatizing reactions such as social ostracism, physical harm, and workplace discrimination (Ogden et al., 2005). Research also shows that keeping family secrets from children including those related to parents HIV status can

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be detrimental to the psychological well-being of parents, their children and the structure of the family (Cottle, 1980). It is also widely accepted that holding back one's feelings results in stress, which negatively impacts physical health (Paxton, 2002). Children who have been told their parents are HIV positive have shown lower levels of aggression and more positive self-esteem than those from whom the information has been kept (Armistead et al., 1995; Murphy et al., 2001).

Parents who are willing to disclose their status often do not know how or when to bring up the subject (Kmita et al., 2002). Parents are also aware of the dangers of non-disclosure, particularly that children might discover the HIV positive status of parent(s) from another source (Nostlinger et al., 2004). There are some studies outside India addressing the problems around parental disclosure (Lee et al., 2002; Rwemisisi et al., 2008; Ostrom et al., 2006). More studies however have been carried out with regard to disclosure by mothers of their HIV status to their children (Armistead et al., 1995; Thomas et al., 2009; Vallerand et al., 2005).

There is little empirically based research within India focusing on the challenges around parental disclosure of their HIV serostatus to their children. (Qiao et al. 2011), further argues that disclosure practices of families affected by HIV living in developing countries are likely to differ because of various cultural and social contexts. This is especially of relevance in the Indian context where children live longer with their parents, are over protected by their parents and parents are still very uncomfortable in talking about issues around marriage, sex and sexuality and information on HIV transmission.

The findings of this study could help provide the necessary background for development of intervention strategies for parents living with HIV, to cope with issues around disclosure.

Comprehensive Health seeking and Coping Paradigm (CHSCP)

Comprehensive health seeking and coping paradigm (Nyamathi 1989), is the framework that has been used to guide this study. This framework has guided many investigations in India (Nyamathi et al. 2007). Originally adapted from stress and coping paradigm (Lazarus et al. 1984) and health seeking paradigm, (Schlotfeldt 1981) the CHSCP proposes that number of factors impact health outcomes of vulnerable population who experience health disparities. Disclosure of one's HIV status can influence health outcomes of Parents Living with HIV who experience health disparities. Furthermore disclosure of one's status especially to children is influenced by many factors. These include socio demographics, situational, social factors and coping responses.

In these study socio demographics factors reflect marital status, age and gender. Situational factors include the

environmental facilitators such health provider settings, HIV status of spouse and coping factors such as age of the child and other psychosocial factors.

METHODS

This is a descriptive cross sectional study, on 115 of 136 HIV positive respondents attending the outpatient clinic of the National Institute for Research in Tuberculosis (NIRT) situated in the Government General Hospital, Chennai, South India. These participants were already enrolled in a TB chemoprophylaxis trial and were attending the clinic for TB prevention treatment and follow up care. The study was conducted between March 2006 and April 2007. All the participants attending the clinic during this period were seen by a medical social worker who screened them for eligibility into the study. Eligible participants were those diagnosed HIV positive who had children aged 6 years or above irrespective of the child's sero status. They were explained in detail about the study and their willingness to be a part of the study was ascertained. Of the 136 eligible participants during this period, 115 were willing to be a part of the study. If willing, they were asked for a convenient time for an interview with a trained medical social worker. Privacy and confidentiality was assured. A semi-structured interview schedule was used for the interview which included both closed and open ended questions. The schedule included information on socio-demographics, details around their perceptions on disclosure; whether they had disclosed their HIV status to their children, reasons for disclosure, reactions to disclosure, plans for disclosure if not done and their fears around disclosure. The open ended questions in the schedule helped to give the participants the ability to express themselves and responses were captured as narratives. These narratives served as qualitative data and have been presented to explain the quantitative findings from the study.

This study was approved by the Ethics committee of the National institute for Research on Tuberculosis (NIRT) which is a premier institute of the Indian Council of Medical Research (ICMR).

Data Analysis

Data were entered in Microsoft Excel and descriptive statistical analysis was performed using SPSS version 14.0. The outcome variable was disclosure; a binary variable with 0 to indicate non-disclosure and 1 to indicate disclosure. Variables including age of parent, age of children, HIV status of the children, number of children, marital status of the parent and HIV status of the spouse were included as independent variables (exposure variables) in the study. Tests of significance (chi square and fisher exact test) were done to identify the

Table 1. Details of Disclosure of HIV status (N=115).

Variables		N	Disclosure status				χ^2 value
			Yes (n=28)		No (n=87)		
			n	%	n	%	
Age	21-30	22	1	4	21	96	24.040**
	31-40	60	10	17	50	83	
	41-50	30	14	47	16	53	
	51 and above	3	3	100	-	-	
Sex	Male	58	11	19	47	81	1.84
	Female	57	17	30	40	70	
Marital status	Married	83	13	16	70	84	12.215**
	Divorced/widowed/separated	32	15	47	17	55	
Number of children	<=2	86	16	19	70	81	8.039*
	>2	29	12	41	17	59	
Age of children	≤10	40	39	97	1	3	34.269**
	11 – 15	36	31	86	5	14	
	15 and above	39	22	61	17	39	
Status of spouse	Positive	71	17	24	54	76	7.481*
	Negative	36	6	17	30	83	
	Don't know	8	5	62	3	38	

*p<.05 **p<.01.

independent variables that were associated with disclosure of parents about their HIV status to their children.

The independent variables that were significant at 5% in the Chi-square test or Fisher's exact test and those that were relevant in the context of the research objective were included in the multiple logistic regressions. Disclosure (Yes/No) was the outcome variable in the Multiple Logistic Regression. Odds ratio (OR) and 95% confidence intervals (CI) were obtained by the multiple logistic regression. Backward Conditional method of entry was used. The final model was the model that gave the maximum change in Log Likelihood (-2LL).

RESULTS

Of the 115 respondents interviewed, 58 (50%) were male and 57 (50%) female. The mean age of the respondents was 37 (SD 6.8) and the mean age of the children was 13 (SD 5.7). Eighteen children were reported as being HIV positive, 89 were HIV negative and the status of 8 was unknown (Not tabulated).

Factors Influencing Disclosure (Table 1)

Twenty eight respondents (24%) had reported disclosure of HIV status to their children.

Marital status ($\chi^2 = 12.215, p < .01$) was associated with disclosure indicating that single parents, those who were widowed, separated or divorced were more likely to disclose than those who were married and living together. Furthermore parents with older children ($\chi^2 = 32.453, p < .01$) as compared to younger; those with more than 2 children ($\chi^2 = 8.039, p < .05$) and older parents ($\chi^2 = 24.040, p < .01$) were more likely to disclose their HIV status to their children. It was also found that disclosure was more likely when both parents were positive. ($\chi^2 = 7.481, p < .05$).

Of the twenty-eight respondents who reported disclosure, 11 (39%) said that the disclosure was done by them, on their own. Five respondents said that the children got to know about their diagnosis under different circumstances which resulted in them having to disclose.

"My children came to the hospital with me and came to know my status on their own. They obviously read the posters on AIDS in the hospital. I had to tell them."(Father 44 yrs, with 3 Female children 13yrs, 16yrs and 21yrs).

Table 2. Multiple logistic Regression - Factors that contribute to disclosure of HIV status to children.

Variables	O.R.	95% C.I.	p-value
Age			
<=40	1.0	Reference	
41 - 56	14.7	3.2 , 68.0	0.001
Marital status			
Married	1.0	Reference	
Divorced/separated/widowed	4.8	1.1 , 22.1	0.041
Status of spouse			
Negative	1.0	Reference	
Positive	4.7	0.9 , 23.9	0.061
Not known	4.0	0.4 , 48.5	0.273
Age of children			
<=15	1.0	Reference	
15.1 – 31	4.0	1.1 , 15.6	0.043

*Wald's test of significance for each category level
-2 LL = 82.4.

Eight respondents said that disclosure was done by a health provider (doctor, nurse). Seventeen (61%) of the respondents had disclosed their status to their children above 15 years , 8 (27%) to children who were between 11 to 15 years and 2 to children 10 years and below the youngest being 6years old.

The circumstances and reasons for disclosure were varied and captured in the following narratives.

“My son always asked me why I go to the hospital so often. Finally when I told him he was so concerned and understanding and reminds me to take my medicines. He does not want to loose me like he lost his father to the disease.” (widow with a 10 year old son).

“My children over heard our conversation during our fight and came to know my HIV status. I had to tell them after that.”(Father, 42 yrs, with 2 sons over 15years).

Perceptions on Disclosure (N=28)

Twenty six of the 28 respondents perceived that the disclosure was necessary. The reasons were varied. Half the respondents felt it was better for them to disclose before they heard it from others. One third of them felt that disclosure would be a beneficial way to warn their children about the dangers of HIV infection and protect them from risk behaviour. Other reasons were that disclosure would result in their children taking care of them when ill (not tabulated). Qualitative data collected through the vignettes have captured some of these perceptions.

“I got HIV as I indulged in risky premarital sex. My child should not make the same mistakes I did.”(Father 36 yr with 9 year old son).

“When I was admitted in hospital my elder son was with me. He got to know my HIV diagnosis then and asked me. I think it is good that the children know my HIV diagnosis. It is only then they will be supportive when I fall ill and we face problems.” (Father 45 yrs, with three children 16 yrs, 14 yrs and 12yrs)

Reactions to Disclosure

Seventeen of the 28 respondents said their children were accepting and understanding when they got to know of their diagnosis. The others reported angry reactions and eight had reported mixed reactions (not tabulated).

“My elder daughter was asking me about AIDS ever since they heard a talk on AIDS in school. I think she had some suspicion as she found my hospital book and asked me what medicines I was taking. I finally took the courage to tell her. She has been so supportive and is very concerned about me. She feels I should wait till her sister grows to tell her. She behaves so mature.” (Widow with 2 daughters 15 and 12 years old)

“My children lost respect for me, when my wife told them about my HIV status and have been very angry with me. My wife does not treat me properly.”(Father 42years with 2 sons above 15years of age).

Multiple Logistic Regression - Factors that Contribute to Disclosure of HIV Status to Children

The independent variables that were significant at 5% in the Chi-square test or Fisher’s exact test and those that were relevant in the context of the research objective were

Table 3. Perceptions about parental disclosure among respondents who did not disclose their HIV status (N=87).

Problems perceived (Multiple responses)	Plan to disclose			
	Yes (N= 47)		No (N=40)	
	n	%	n	%
Indifference	8	61	14	35
Over protection	1	8	3	8
Share with others	1	8	8	20
Loose respect	2	15	10	25
Others	1	8	5	12

included in the multiple logistic regression. The most significant variables which influenced disclosure were age of the parents, 41-56 years (Adjusted OR = 14.7 C.I (3.2, 68), p-value: 0.001), divorced /widowed (Adjusted OR = 4.8, C.I (1.1, 22.1), p-value: 0.041) and children above 15 years (Adjusted OR = 3.1, C.I :(1.1, 15.6), p-value: 0.043) (Table 2).

Perceptions about parental disclosure among respondents who did not disclose their HIV Status (N=87) (Table 3)

Of the 87 participants who had not disclosed, 47(54%) reported that they did consider disclosing their HIV status to their children. While twenty (45.5%) said that they were more likely to disclose when the child was between 11-15 years, twenty-three (55.3%) said that they had planned on disclosure when their child was above 15 years (not tabulated). Among the 87 respondents, 12 of them had a child who was HIV positive, above 12years of age (not tabulated).

The most repeated reasons for disclosure were to protect their children from risky behavior and to take care of them when ill (not tabulated).

"Since I have a son I need to make sure that he is careful as he grows older. I do not want him to get into any bad behaviour like sex, drugs, alcohol. My son should know that his father died of HIV and he left me with the disease. My son should know how much I have gone through to take care of hi."(Widow, 39yrs with a son 9 yrs old)

Thirty eight (81%) respondents felt that they preferred to disclose their status to the children themselves and 7 of them said they would like the services of a counselor. Twenty seven percent of those who planned to disclose (47) and 85% of those who did not plan to disclose (40) envisaged problems on disclosure. The difference was significant ($\chi^2=28.605$, $P<0.01$). The main problems they feared in disclosing was ascertained from an open-ended

question. The major reasons were indifference (14%vs35%), loss of respect (10% vs. 25%) and sharing of information to others (8%vs20%).

DISCUSSION

Findings from this study reveal that only a quarter of the respondents have disclosed their positive status to their children. Most studies have reported disclosure by mothers (Armistead et al. 1995, 1999; Thomas et al. 2009) but this study also reports disclosure by fathers. Furthermore the study findings have also pointed out, that children have come to know their parents HIV status on their own in various circumstances. These included during hospital visits or support group meetings when they accompanied their HIV positive parent and overheard what was being discussed between their parent and the health provider. Few also reported that they read their hospital booklet where their HIV status was recorded or some others that they heard about their HIV status during a domestic quarrel between their parents. This is worrisome as disclosure if not done properly with information being passed on to the child in a manner that he or she may not comprehend, could have adverse effects on the child. This also needs to be understood keeping in mind that disclosure was more among the widowed and divorced and the fact that these children may have already experienced the trauma of separation or death. Disclosure among those widowed or separated has also been reported in another study (Armistead et al., 2001). This could be attributed to the fact that those parents who have been separated or widowed may find it necessary to disclose their status to their children, having to face the illness alone. There is always the lurking fear of death and the uncertainty of the future of their children lest something happens to them and the need to prepare them for any eventuality. Parents have also expressed that it was better for them to disclose rather children getting to know their diagnosis

through somebody else. However there were parents who expressed helplessness and sought help in disclosure. It is also worrisome that one tenth of the parents, who had not disclosed, had children who were above 12 years of age, who were HIV positive themselves. While they were faced with the challenge of disclosing their status, there was also the burden of the child's HIV status which remained undisclosed.

Findings also reflect the concern parents have with regard to the outcome of disclosure, especially among those who planned to disclose and among those who did not plan to disclose their diagnosis. The major concerns were related to loss of respect and indifference and their worries around the information being shared to others. These findings are in keeping with other studies which have reported that common barriers to disclosure cited by parents include fear of rejection or loss of respect, negative emotional reactions from their children, and inadvertent disclosure to others by them (Murphy et al., 2001; Thomas et al., 2009; Vallerand et al., 2005; Kmita et al., 2002; Pilowsky et al., 2000; Waugh 2003; Kouyoumdjian et al., 2005; Corona et al., 2006; De Matteo et al., 2002; Sandelowski et al., 2003a; Scrimshaw et al., 2003).

It is also interesting that those who disclosed perceived that the disclosure was necessary as they felt that disclosure would work towards their children being careful to protect themselves, be more responsible and that they may also help take care of them when ill. This is similar to other studies that reported potential benefits of disclosure which included formal or informal social, emotional, financial support for the child and for clarifying misconceptions the child holds regarding contagion and transmissibility of HIV (Chandra et al., 2003; Zay et al., 1994).

The strengths of the study is that it has focused on an understudied area in India and provides relevant information to health professionals which needs to be incorporated in HIV care and support services. These services often are limited to issues around adherence for HIV medications and the concerns around disclosure are often overlooked. This is important for a holistic approach aimed at providing a better quality of life for parents living with HIV and their children. There are however several weaknesses. The data does not capture disclosure at different stages of the illness as well as its impact on the health outcomes of parents living with HIV. This is also a clinic based study and therefore not representative of the wider population of people living with HIV thereby limiting the generalization of the findings.

CONCLUSION

The study findings conclude low rates of disclosure and that disclosure was most often not planned and happened in circumstances beyond their control. This

needs to be addressed in the context that health providers most often do not focus on the issues around parental disclosure. Parents living with HIV are still coping with the illness in an environment that is characterized by stigma and fear and discrimination. Study findings reflect the need for intervention strategies among parents who require disclosure support services to equip and guide them through the process of disclosure thereby promoting a quality of life for parents and their children.

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