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# HIV Disclosure: Parental Perceptions in Disclosing Perinatally HIV Infected Children about their HIV Positive Status

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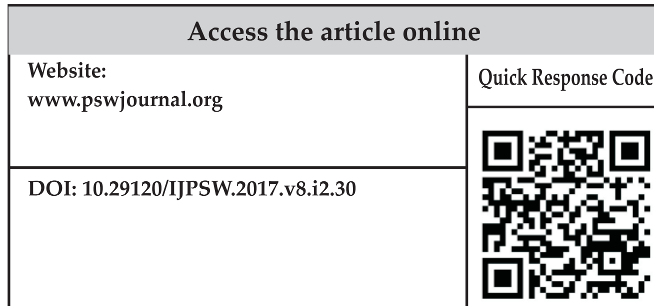
## ABSTRACT

**Background:** The increased access to antiretroviral treatment resulted in increased survival rates among the children infected with HIV/AIDs and also led to the improved quality of life of sero-positive children. The chronic medical conditions in the paediatric population pose a range of potential psychosocial challenges and also disclosure of HIV status to the positive children. The current study aimed to understand the Parental Perceptions on Disclosure of diagnosis to their HIV Positive Children. **Methodology:** For this purpose the researcher used qualitative method in which 13 parents were interviewed to understand the parental perception about disclosure of HIV status to their perinatally infected children and challenges in disclosure. **Results and Conclusion:** The results were analyzed using thematic approach. The findings of the study showed lack of understanding of importance of disclosing HIV status to their positive children, fears of post disclosure impact and lack of consensus among few parents regarding who should disclose HIV status to the infected children and adolescents.

**Keywords:** Children, disclosure, HIV/AIDS, perinatal, parents

Globally, HIV/AIDS is the fourth leading cause of mortality in the world, and it is responsible for more than 7.7% of mortality in children less than five.[1] Around 3.3 million children across the world is living with HIV/AIDS.[2] It was estimated that India has an overall prevalence of 0.31%. Approximately 50,000 children below 15 years are infected by HIV every year. India has the third highest number of estimated people living with HIV in the world.[3] The increased access to antiretroviral treatment resulted in increased survival rates among the children infected with HIV/AIDs and also led to the improved quality of life of sero-positive children. The chronic medical conditions in the paediatric population pose a range of potential psychosocial challenges including disclosure of HIV status to the positive children.

Disclosure of HIV status has become an important issue as HIV infected children on ART become older enough to understand the significance in order to maintain treatment adherence. Disclosure has been shown to influence treatment adherence; better understanding of HIV status; treatment retention; better relationship with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parents; high self-esteem; better coping ability of adolescents to deal with associated stressors and stigma in the society; and improved health outcomes.[4-7]

Despite of benefits of disclosure, one of the greatest challenges for parents and caregivers is the question of when and how to disclose HIV diagnosis to one's own infected child/adolescent. Parents/caregivers are also reluctant to disclose the HIV positive status to the perintally HIV infected children due to parental sense of guilt, and fear that the child would not keep diagnosis confidential which may lead to social rejection and ostracism in the society. There is little understanding to know about parental perceptions, concerns and barriers related to disclosure of child's HIV status to their own HIV infected children in India. The current study aimed towards this direction.

## METHODOLOGY

The study was conducted at Milana, a Non-Governmental Organization (NGO), which provides care and support for the Person Living with HIV/AIDS in Bengaluru. The study conducted between January - December 2015. Thirteen (13) HIV positive parents were recruited for the study using purposive sampling technique. Parents with seropositive HIV status, who speaks Kannada and willing to participate in the study were recruited for the research. Parents who were unwilling to participate with cognitive and neurological deficits were excluded for the research. Out of 13 parents, 9 were mothers, 4 were fathers participated in the study. The participants' age were ranged between 26 - 45 years. Qualitative data were collected through focus group discussion method.

Powell[8] defines a focus group as a group of individuals selected and assembled by researchers to discuss and comment on, from personal experience, the topic that is the subject of the research. Focus groups are a form of group interviewing involving interviewing a number of people at the same time, the emphasis being on questions and responses between the researcher and participants. Focus group relies on group discussion and where the participants are able to talk to each other about the topic of research interest. It allows the participants to share views with each other with relevance to the topic under the study. The discussion is usually focused on a particular area of interest.[9]

In the current research the focus group discussion was conducted in regional language Kannada after taking informed consent from the participants. The structured focus group discussion guide was prepared covering aspects of parental perceptions about HIV status disclosure to their infected children and adolescents. The structured guide was validated by the experts before administering to the participants. The focus group discussions lasted for about two hours. The actual focus group discussions were audio recorded later transcribed and translated into English. We employed thematic analysis to analyze the data. Notes and open codes were generated and organized manually and similar codes were grouped into categories. We identified and discussed a hierarchical scheme of specific themes, issues, and problems that emerged from the discussions data. Themes that recurred with high frequency and the themes with strong emotional content received higher codes.[7] Analysis included thorough reading of transcripts, grouping of themes with similar information while checking for codes, clustering codes into common themes. Totally four themes were emerged which are as follows: perceptions towards disclosure, parental views towards appropriate age for disclosure, impact of disclosure and perceived barrier in disclosure.

Ethical Clearance: Ethical clearance was obtained from Human Behavioural and Ethics Committee of the NIMHANS, Bengaluru

## RESULTS

### Perceptions towards Disclosure

With regard to perceptions towards disclosure and who should disclose HIV status to infected children and adolescents, the opinions of parents were different. However, all the parents opined that the children have every right to know about their HIV status before they get incorrect information from other sources which may affect their mental health. Five parents who have already disclosed HIV status to their infected children feels relieved that they are no more keeping their children in darkness by giving false information like they done in the past. Parents expressed that they have disclosed because the child was started asking repeated questions regarding his/her routine hospital visits. Reasons for non-disclosure by eight parents were fear of hurting the child, fear that the child would blame, hate, judge and reject them, fear that the child would be angry

and may harm himself impulsively, feel that child is too young to understand the HIV diagnosis and may not be able to maintain secrecy which may lead to social ostracism in school and community. One father and mother reported that disclosing HIV status to their grown up child would lead to answering difficult questions related to death and dying for which they were not prepared and comfortable to answer.

**Quotes:**

- *We don't have enough courage to reveal their HIV status, so we kept ourselves quiet by waiting for an appropriate time. If the child ask how we got HIV, we will not be able to answer difficult questions…. this worries me a lot"*
- *"My son is on ART medication. Only thing he knows that he must take medicines regularly. Many times he had asked me..."Daddy why should I take these medicines regularly? I have not clearly explained about his HIV status except that I have told him that he has to take medicine to be strong and improve CD4 level. But he doesn't understand it and keep asking me same questions. I really don't know what he will think when he knows how HIV being transmitted …… he may hate me and blame me".*
- *"I have told my daughter that you have to take medication to become strong and have more CD4 in the blood otherwise you may become weak and often sick"*

**Parental Views towards Appropriate Age for Disclosure**

With regard to parents' opinion towards appropriate age for the disclosure of HIV status, most the parents reported that disclosure process should begin as early as 5 years age for partial disclosure and 12 – 15 years for full disclosure. When specially asked about right time to tell the child about their HIV disease, the opinion of the parents varied - few felt the child should be told depending upon the level of maturity and understanding ability of the disease whereas others expressed puberty was the right time to reveal the child. When asked about the person who should be responsible for disclosure of HIV status to children, six parents expressed that the parents are the right and appropriate person to disclose to children; three parents felt that counsellors or doctors or nurses should support and initiate disclosure process, however, the disclosure should be done by the parents and four parents felt doctors, counsellors or nurses are the right person to disclose HIV status to the infected child. One of the common things expressed by the all the parents were of fear of getting confronted with questions related to how the child became infected. They were unsure of how the child would react and how to handle post disclosure emotional reactions of the child. With regards to why parents should take the lead in disclosure, the common reasons expressed by them were listed below:

- The child is close to parents/caregivers
- The child trust parents/caregivers and accept the fact if the parents disclose
- Parents are available to monitor the child's reaction to disclosure
- Parents or caregivers know how child react as they are aware of temperament of their child.
- Parents aware of child's understanding ability and disease condition of the child depending up which parents can take decision for appropriate time for disclosure and nature of disclosure.

**Quotes:**

*"We should reveal HIV status to child depending upon his/her maturity level. For younger child we should give importance the need for taking medication by explaining in simple language"*

*"I told him about HIV because he is a bit old to understand it"*

*"I may not be able to answer difficult questions of my child ……if a counsellor/a doctor sit with me while disclosing, it would be helpful in handling my own anxiety in answering difficult questions related sexuality, treatment related aspects, death and dying"* .

*"I may not be able answer if the child asks how he got infected with HIV. How can I tell it's through sex? What will he think about us? It's hard to answer the question….."*

*"If I tell my daughter that she is HIV positive, she will definitely ask me how she got infected. This is not easy for me to tell her about how she got it. What she will think about me and my husband…..I have to explain about sex and about our HIV status too…. it's hard"*

**Impact of Disclosure**

Parents reported mixed reactions - positive and negative reactions from children following the disclosure of their

HIV status. Four parents reported improved relationship and increased familial closeness and improved drug adherence over time as a positive result of disclosure. Some of the negative reactions following the disclosure of HIV status to infected children reported by the parents were fear, shock, refusing to going to school, disbelief, withdrawn behaviours, crying continuously, irritability and being anger towards himself and towards parents for transmitting illness to them, suicidal behaviours and depression.

**Fear**

*"After the disclosure he asked am I going to die like my father? Are you also going to die?"*

**Shock**

*"She was in shock. Her jaw dropped hearing the word HIV. She did not speak to me whole day except crying. My heart broke down looking at her face…."*

**Disbelief**

*"He just asked me how it could happen to him as he has not done any bad things to others"*

**Withdrawn and Crying**

*"I disclosed HIV status to my daughter with the help of counsellor in ART centre after she attained menarche. She was in a state of shock, started crying continuously. She refused to take food for so many days. I have also noticed lots of behavioural changes after disclosure…. She has become withdrawn, prefers to be alone, and doesn't talk with me. I feel guilty ……"*

***Irritability and Anger***

*"My older son yelled yet me and said how I could do it to him and his mother? He has been hostile towards me since then…… doesn't not show any affection towards me"*

**Suicidal behaviours and depression**

*"Recently I have noticed gradual changes in the behaviours of my son after knowing about his HIV status from me. He frequently would get angry towards me without any reason; cry often and threatens to kill himself…… he tried several times to commit suicide by injuring himself with a blade…. cutting wrist……I don't know how to handle him……day-by-day things are worsening….."*

**Perceived Barrier in Disclosure**

Some of the barriers reported by the parents in disclosing HIV status to the infected child are: lack of culturally appropriate disclosure materials in pictorial forms in regional languages to explain the children regarding HIV/AIDS, lack of training, education and support in disclosure process from the health care providers from the ART centers. They felt that counsellors should prepare them adequately in advance to answers anticipated questions from the infected children so that they can provide scientific information to the children depending upon their level of maturity and understanding ability.

*"If child ask me about what is CD4 count I will not be able to explain to him until and unless I have some knowledge about it"*

*"Counsellor should prepare what answers to be given to the child when it comes to death and cure for HIV/AIDS. My son has been asking me, 'Is there any cure for HIV/AIDS? 'he also asked me whether he can marry and have children …..I really don't know what to tell him"*

*"We need simple story books with lots of pictures to explain to kids about virus, CD4, and importance of taking medications to kids".*

## DISCUSSION

The current study explores perceptions, reasons and experiences of parents in disclosing HIV diagnosis to their infected children. All the parents believed that children have a right to know about their HIV diagnosis and few parents had already disclosed HIV status to their infected children. The data sheds the light on factors that influence parent's decision to disclose HIV status to infected children. Most of the parents viewed that children's age, perceived maturity, disease related factors, parental HIV related factor, and temperament of the child are the some of the indicators to make decision for appropriate time for disclosure. At the same time parents also feared that children would not keep their HIV status confidential resulting non-disclosure by few parents. The reasons for not revealing the HIV status in this research finding is consistent with many research findings.[10-12] Opinion about optimal age of disclosure varied. Caregivers from South Africa endorsed older ages for both events – 11 years for general discussion and 12 years for HIV specific information[13] (and 10-11 years for partial disclosure and 14-15 years for full disclosure.[14-15] The findings of the current research is consistent with literature where

parents felt that that disclosure process should begin as early as 5 years of age for partial disclosure and full disclosure at age of 12-15 years. The finding of the study also highlights the importance of developmentally appropriate planned disclosure by parents/caregivers with the support of health care provider to disclose a HIV status to the infected children and adolescents. The majority of parents in this research felt that the parents are the right person to disclose HIV status to their infected children as the children trust them. The parents also stressed the need for developing culturally appropriate disclosure materials in limited resource setting like India. Additional research is needed on effective strategies of disclosure and the clinical, emotional and social impact of disclosure on HIV infected children in resource limited settings as many parents reported behaviours and psychological disturbances in their children following disclosure. Longitudinal studies that follow children through the disclosure process need to be conducted to assess the post mental health impact of disclosure which would allow clinicians and other health care providers to deliver appropriate services and support to HIV infected children and their families.

## LIMITATION

The current study has few methodological issues which need to be mentioned. The study was conducted with smaller sample from one non-governmental organization. Hence, the findings of the study could not be generalized due to inadequate representation of sample from many organizations.

## CONCLUSION

This study clearly brought the issues and concerns of parents of HIV infected children in relation to disclosing HIV status to their perinatally infected children. The findings of the study highlights the need for developing culturally appropriate HIV disclosure materials and guidelines for parents/caregivers of perinatally HIV infected children in India context.

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