

Necessity of Systematic HIV Disclosure in HIV-infected Families: Committed Communities Development Trust's Approach and Intervention

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Due to greater access to antiretroviral therapy, telling adolescents that they are HIV-infected and/or affected has become an integral and intricate part of the treatment protocol. Despite growing treatment resources from public and private sectors, there is a lack of systematic disclosure for children and adolescents affected and living with HIV/AIDS. Committed Communities Development Trust, a non-government organization working with children and adults infected with and/or affected by HIV, conducted a mixed-methods, cross-sectional study with 33 families in their home-based care program to evaluate their current disclosure protocol. The findings indicate that these experiences implementing and fine-tuning this protocol provide useful lessons for other Indian non-government organizations working with HIV-positive families.

Key words: *Acquired immunodeficiency syndrome, Children, Counseling, HIV.*

HIV-positive parents carry the burden of having to disclose their own status to their families, and the even greater challenge of having to inform their seropositive children of their status. Beyond conveying this information, they must also explain in an age-appropriate manner that HIV is a chronic illness that must be managed with a daily regimen of medicines they must take for the rest of their lives. An additional difficulty is that parents need to be able to talk openly about sex, a topic that is taboo in Indian families. They must learn to talk about how the virus is transmitted, answer potential questions about how they became infected, and talk to their adolescent children about how to protect their future sexual partners.

The Committed Communities Development Trust (CCDT), a non-government organization (NGO) has been working with marginalized populations in Mumbai since 1990. The organization's mission is to combat hunger, disease, and discrimination through community action with a core focus on children. CCDT's home-based care (HBC) program works with HIV-infected and affected families through three Mumbai-based offices offering physical, medical, nutritional, emotional, psychosocial, and palliative services in the home environment. The HBC program provides care and support to more than 600 families and over 1000 children every year with the goal of assisting them to return to good health and economic self-sufficiency [1]. Social

workers and other staff support families and children throughout the disclosure process, which can take several years as children absorb the information about a parent's and/or their own HIV status and learn to assimilate it. CCDT's disclosure policy and process provide a practical example for other NGOs assisting HIV-positive parents to talk to their children about their own and/or the child's status.

DEFINING DISCLOSURE

Disclosure can be separated into three categories: no disclosure, partial, and full. No Disclosure is when one is told nothing about HIV or any other illness. Partial Disclosure involves giving some but not full information about the illness. The person may be educated about the importance of taking medicine in order to keep their illness at bay and even learn how an illness can be transmitted without learning that they are infected with HIV. Full disclosure is when one is told the name of their illness, disease-related information (process and transmission), how they became infected and what they must do to manage the virus and avoid transmitting it to others [2].

WHO DISCLOSURE GUIDELINES

World Health Organization (WHO) policy emphasizes that systematic disclosure is a critical part of HIV treatment and support [3]. WHO disclosure guidelines encourage pediatric disclosure, highlighting the

importance of dispelling parents' or caregivers' fears about negative outcomes of telling children the truth about their status or that of a parent. According to the guidelines, disclosure to children about their own HIV status is necessary when there is a chance of health benefit with minimum psychological and emotional harm. Disclosure to children of their parents' or caregivers' HIV status is necessary when there is a possible health benefit to both HIV-infected and/or affected children and no further harm to the caregiver's health status. Overall, the guidelines suggest that disclosure should be gradual, age-appropriate, and empathetic [3]. The WHO guidelines are not context-specific and do not differentiate based on age, maturity and psychosocial development; however, they provide a useful foundation that service providers can use to develop detailed, culturally appropriate disclosure strategies.

CHALLENGES AND STRATEGIES

Disclosure has been studied in a number of contexts and results show lack of consensus among health workers and affected families on when, how and under what circumstances disclosure should be carried out. Overall, research on family and pediatric disclosure in resource-limited settings is heavily focused on sub-Saharan Africa [4-9]. Forty semi-structured interviews from healthcare providers in Cape Town, South Africa reported that children should be notified about the basics of the illness at the age of 6 years, with more specific discussions regarding HIV at age of 10 years. The data further indicated a need for interventions to assist healthcare providers and caregivers in effectively discussing the illness with families [10]. A study from South Africa, which gathered data through focus group discussions reported the most frequently cited reasons for not talking about the illness was: fear of stigma, discrimination, and death; the influence of television and media; not knowing how to talk to children about such a sensitive topic; and social isolation. In most cases, parents described waiting to talk about the illness out of concern that it would frighten their children [11].

Published research specific to Indian context is scant. We could retrieve only two journal articles and one evaluation report [12-14]. Many children in India find out about their HIV status indirectly as a result of their frequent doctor visits, intensive medicine regimens, and overhearing caregivers doctors' conversations [1]. A study conducted in Northern India assessing the patterns of HIV disclosure in 145 children over the age of five found that children were told about the illness between the ages of eight and ten years [12]. Another study in

Delhi with fifty caregivers indicated that 14% of children were aware of their infection, and only 6% were given factual information about the illness [13]. Barriers to disclosure in the studies included stigma and caregiver's lack of knowledge, communication strategies and emotional preparation [12,13].

A 2014 mixed-methods evaluation of pediatric disclosure practices by four NGOs provides the most in-depth, relevant data [13]. All four NGOs demonstrated expertise in the field with experienced staff trained to support family and pediatric disclosure. Each NGO employed self-designed interventions with emphasis on adherence to antiretroviral therapy (ART), nutrition, hygiene, and self-care. The study reported CCDT staff discussing HIV status with children in their residential care program with an emphasis on finding a balance between maturity level and growing curiosity. In particular, a child's maturity level guided provision of information on modes of transmission, CD4 count, and the importance of ART adherence. The evaluation findings suggest that all four NGOs played a critical role in encouraging caregivers and parents to talk about the illness with children, but greater collaboration is required with ART centers and national institutions [14].

CCDT'S DISCLOSURE PROCESS

CCDT has been implementing its family and pediatric disclosure protocol as part of their home-based care program in Mumbai, India. Over the last 20 years, CCDT has designed a systematic and culturally sensitive process that guides families through the disclosure process over time. Full disclosure is promoted with all families in the HBC programme and particularly emphasized in the following situations:

- When a seropositive adult client is not disclosing status to his/her partner but is having sexual intercourse;
- In a child-headed family where a child is seropositive;
- When a seropositive single parent has very poor health and seropositive children;
- When a child is taking care of an HIV-infected parent whose health is poor.

In the beginning of the process, parents or caregivers meet with a social worker and counselor who provide psychosocial support and initiate a conversation about the importance of informing children about the illness [1]. Children are included in the conversation once the parent is ready to share information about their HIV status or the child's (**Box 1**). CCDT also organizes a three-day residential camp outside of Mumbai to provide additional

BOX 1 KEY POINTS IN HIV DISCLOSURE PROCESS BETWEEN PARENT AND CHILD

- Conversation initiated between ages 11 and 15 years
- Age-appropriate information given to child
- Gradual process guided by child's maturity level
- Conducted with clear guidelines set with assistance of a counselor
- Timing determined by parent's readiness to broach the topic
- Ongoing follow-up provided by counselor to assist with child's questions and acceptance process

counseling support to parents and introduce the illness to children in an informal, supportive group setting. The camp counselors conduct various games and role-plays to discuss basics of HIV, living with the virus, coping mechanisms and the importance of disclosure [1,14].

RESULTS FROM THE DISCLOSURE EVALUATION

A small process evaluation was undertaken by CCDT in 2013 with 33 families, who had completed the disclosure process at least two years prior. Within each family, one parent and one child were interviewed by an external researcher (the corresponding author) about their insights on the impact of disclosure on family relationships and children's understanding of their own or their parent's illness. The interview questions focused on five broad themes: (i) medicine and illness; (ii) shame, blame, and judgment; (iii) stigma, fear and discrimination; (iv) talking about HIV status; and (v) the child's daily interactions with family.

The study findings suggested positive progress from the families' initial enrollment into the HBC programme. Following disclosure, most of the parents reported feeling less fearful of death and over half of the parents indicated feeling less stressed about shame, blame and judgment. Both parents and children communicated positive outcomes such as healthier diet, improved family relationships and taking better care of family members. As one mother explained her motivation for disclosing her HIV status to her children: *"Being a single mother, I get blamed a lot about my positive status. I fear for my children. People don't have problems spreading rumors. I wanted to disclose my status to my children so they know not to blame their mother."* An adolescent girl reported feeling greater empathy for her father once she learned of his illness: *"I was always angry at my father for being sick and strict with me for going out late at night. I never understood why he was tired all the time. When I attended the residential camp, I understood what he was dealing with."*

Parents and children suggested eleven to fifteen years to be the appropriate age frame to inform children about the parent and child's HIV status. The children demonstrated their understanding of HIV by explaining modes of transmission and importance of medications. Many reported understanding their parents' initial hesitation to talk about their own illness or the child's. Overall, children reported appreciating the opportunity to learn and talk openly about their or their parent's illness, and did not blame the parent.

DISCLOSURE PROCESS AND FOLLOW-UP

Getting families to talk about HIV continues to be a challenge for CCDT due to cultural beliefs and stigma. Parents still struggle to disclose due to the fear of being exposed and isolated from society. Families also expressed the need for post-disclosure follow-up to offer children direction on scholarship opportunities, college admissions, marriage and career guidance. Children asked for more opportunities with the organization to volunteer in community events and HIV/AIDS-related campaigns. They also requested assistance with job applications and life-skills seminars on self-reliance and leadership skills.

LESSONS FROM CCDT'S EXPERIENCES

CCDT's emphasis on the importance of parent-child disclosure seems to be a positive step for the families participating in the home-based care program, enabling them to discuss the illness freely and to work together on improving their health, treatment adherence, and relationships. The organization's twenty-plus years of experience supporting families affected by HIV shows that disclosure is not a snapshot event; rather, it is a long-term process involving ongoing follow-up and guidance that can influence the present and future emotional wellbeing and self-care of both parents and children. However, there is a lack of guidance on timing and impact of disclosure. On a national level, there is a greater need for stronger collaboration between health care providers and NGOs to learn from effective implementation of programs [1]. Through culturally appropriate guidelines, stronger protocols, and collaboration at a national level, effective disclosure protocols are certainly achievable.

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