

**UNDERSTANDING NEEDS OF CHILDREN
LIVING WITH OR AFFECTED BY HIV AND AIDS**



**SAMRAKSHA
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SAMRAKSHA
Adding Life To Years

UNDERSTANDING NEEDS OF CHILDREN LIVING WITH OR AFFECTED BY HIV AND AIDS

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Key Findings from the Needs Assessment Study on Children Affected by HIV and AIDS

INTRODUCTION

AIDS is redefining the very meaning of childhood for millions, depriving children of many of their human rights – of the care, love and affection of their parents; of their teachers and other role models; of education and options for the future; of protection against exploitation and abuse. The world must act now, urgently and decisively, to ensure that the next generation of children is AIDS-free.

A Call to Action: Children, the missing face of AIDS, UNICEF (2005)

During the last decade, the AIDS pandemic has seriously hindered the progress towards the child survival and development goals set with such hope at the World Summit for Children in 1990. This is particularly true of the countries with adult HIV prevalence of above 1 per cent. It is also true of countries like India, where although adult prevalence is less than 1 percent, the sheer number of people living with HIV translates to very high numbers of affected children.

In India, the impact of the AIDS crisis has just begun to fully emerge. Children affected by HIV includes children in a wide range of situations: children having HIV or AIDS, children whose parents or siblings are living with or have died due to HIV or AIDS, children whose households are strained due to the presence of other children affected by HIV, and children who are vulnerable to acquire HIV infection. In India, children affected by AIDS are still in the process of being identified. Yet, it is estimated that India has the largest number of AIDS orphans with the UNAIDS estimating the number to be 2 million. Also nearly 4 % of the 2.4 million HIV infections in the country is believed to be among children, due to vertical transmission. Despite significant reduction in vertical transmission following intense focus on preventing parent to child transmission, new HIV infections among children are still being diagnosed (UNAIDS , 2006; UNICEF, 2005).



India has been struggling to provide basic amenities to vulnerable children. In the case of children affected by HIV, the situation is compounded by the nature of HIV and its additional economic and psychosocial impact. The NCAER reports a 9.24% drop in household income in families where even one member is living with HIV. The economic impact of HIV on the family affects the child's access to schooling, nutrition, shelter and health care services (Pradhan et.al, 2006). The psychosocial impact of having to care for a sick and dying parent and parental death, topped by HIV related stigma and discrimination, is also significant. Wide access to ART has significantly reduced deaths. However, late access of treatment, complications due to poor nutritional status, inadequate management of side effects and co-morbidities still make death and dying part of the existing HIV scenario. Many of the children in these situations end up growing without any adult care.

Samraksha has been working in the HIV sector for more than 15 years now. It offers a continuum of HIV related care, including medical and psychosocial services for individual and families affected by HIV. The significant number of HIV related deaths witnessed by the organization brought up the important question of what would happen to the children following the death of one or both parents. Other questions emerged: How had HIV impacted the child's life, how did the child respond to its own or its parent's illness and what needed to be considered while designing interventions for these children. This highlighted the need to conduct a needs assessment of the children affected by HIV, in order to design meaningful interventions.



METHODOLOGY

The universe for the study was people living with/families affected by HIV, who were registered with Samraksha's urban and rural care and support programmes. Convenience and purposive sampling was used to select 42 children and their carers from rural areas, and 49 children and their carers from the urban areas. This included a mix of both children living with HIV and those affected by HIV. The rural sample consisted of 22 children living with HIV and 20 children affected by HIV, and the urban sample of 25 children living with HIV and 24 children affected by HIV. The carers of the children were also interviewed. In most cases, this was the mother of the child. In some instances it was the father or the grandmother.

The study used quantitative methods for data collection, which were adapted from two standardized international tools: the Child Needs Assessment Toolkit developed by the Education Sector of the World Bank and the Task Force on Child Survival and Development (World Bank 2002); and the Situational Analysis Toolkit, developed by Family Health International, following a participatory situation analysis of orphan and vulnerable children affected by HIV (FHI 2005).

In this document some of the key findings from this study are discussed, specifically those which focus on the child's life and household circumstances. The findings on the psychosocial impact of HIV are also discussed. These are critical to understand the multiple ways in which HIV affects children, and has implications for developing child-sensitive interventions for children affected by HIV.



MAIN ISSUES OF CHILDREN AFFECTED BY HIV

Effect of HIV on Household

The major impact of HIV on children has been the death of the father. As in most cases, he was the wage earning parent, his illness or death affected the family income. Almost 80 percent of the rural respondents reported a monthly household income of less than INR 2000 (about USD 40), with 43 percent reporting less than INR 1000 (about USD 20). Although urban households reported slightly higher levels, a majority of the households had a monthly income of less than INR 5000 (about USD 100). Mothers were the primary care-givers for more than 60 percent of the children, and more than 60 percent of these mothers were widows or single women heading the household.

A majority of the caregivers, especially in the rural areas, reported that they have less money and food in the family following the death of the parent. Although most families had a basic three meal diet, they reported that they were not always able to meet the special requirements of children living with HIV. About 48 percent of the rural caregivers reported that they were not happy with their ability to satisfy the nutritional requirements of the child. Only about 23 percent of the carers were able to give special food to the child during periods of illness, while another 23 percent reported that they gave additional quantity of the daily food, often just to pacify the child. Many of the children themselves reported having to do without certain things, including special food or toys, following the parent's death.

Parental death or illness was also reported to affect the child's school going. Almost 30 percent of the rural respondents mentioned that the children had dropped out of school because of a parent's ill health. About 20 percent also mentioned drop in school performance or attendance following a parent's death.

It was found that parental death also resulted in an increased need for the child to share the household burden. They had to do more work at home or on the fields, or had to care for the living parent or younger sibling as a consequence of the illness or death of a parent.

All these highlight the vicious cycle of HIV within the families, where HIV results in economic problems which restrict access to certain services for the family and the child. This further aggravates the economic problems, and the vulnerability to HIV.



The impact of HIV was also reported to have resulted in other changes in the child's life. For many it had meant a shift to a new household with grandparents or other relatives and consequent life adjustments. This change was also hard to cope with; many children reported getting disturbed if people scolded them or talked sharply to them in their new homes.

Emotional Impact of Ill Health

Most carers reported children felt upset and worried after hearing about the parent's health condition. Other reactions observed included a demand for attention, a fear of abandonment, a feeling of being neglected or a sense of increased pressure to do household work.

Carers reported that children cried or became silent and withdrawn when they became aware of their own HIV condition. Sometimes, they asked questions on how long they should take medicines, why they were taking medicines all the time, and when they would become like other children.

Over 90 percent of the children themselves reported feeling upset, because of ill-health of parent. They reported wondering what is happening to the parent and feeling bad when they saw their parents suffering. Many of the children reported that they wished they could make their parents better as before, or take care of them in some way and find some medicine to cure them.

The findings show that parents do not always disclose their HIV status and its implications to the child. Among the respondents, only about 38 percent of the carers in the rural areas and 14 percent of the carers in the urban areas reported that they had disclosed their health status to the child. Even this was not complete disclosure; sometimes parents had only told the child that they had a terminal illness or some other illness like tuberculosis.

Disclosure to the child happened in different contexts. For instance, parents reported that they talked about the child having to do more household work because they were sick,; or they talked about being worried about the child's future in case of their own ill-health or death. It was seldom a planned disclosure where carers would explain things to the child and help him/her understand.

The study revealed parental self-stigma in certain instances, where parents spoke to the child negatively of their own health status and hoped that the child would



not get similarly affected. But in the absence of any discussion on the issue, this only confused the child more.

Even in instances when the child was also living with HIV, nearly 40 percent of the rural child respondents and 80 percent of the urban child respondents were not specifically aware of their HIV status. However, irrespective of whether there had been disclosure to the child or not, children were aware that there was a health problem. They also questioned their carers about their own/ carer's frequent illness and the need to take medicines constantly.

Almost all the carers felt that it is important to speak to the child about HIV and related issues, but less than 10 percent had actually spoken about it, even as a general issue in their homes. Many reported a hesitation to talk about the issue, especially to young children. Parents felt that they required the support of a professional, a doctor, counselor or some other health care professional who could talk and explain these issues better to the child.

Coping with Parental Death

The toll of HIV on the child's family had been heavy. 79 percent of the rural respondents and 59 percent of the urban respondents reported that at least one parent, in most instances the father, was dead.

Most children reported drawing conclusions about their parents' ill-health and subsequent death. But only about 50 percent reported being aware of the cause of the death and having had this information communicated to them properly. In most other cases, they made inferences based on what they heard and unconsciously grasped from adult conversations. In an already emotionally fragile stage due to the parent's death, they could not fully comprehend what had happened, or talk to someone and ask them questions about it. This added to their distress.

Most of the children wanted to speak about their dead parent/parents. However, their carers, especially if it was the surviving parent, did not frequently talk about it due to their own grief, or for fear of upsetting the children. Children, therefore, spoke to other family members like grand parents or siblings about the dead parent.

Caregivers talked to children about parents' death mostly in the context of how it currently impacted their lives. This would be, for instance, mothers speaking to children of their having to become more involved in work because the father is dead, or they



themselves were sick. Sometimes, they also communicated their fears about the child's future in the event of their own death.

All children reported missing their parents and frequently thinking about them in different contexts: at night, when somebody scolded them or when they had to work more. Almost all children had preserved some belonging which helped them remember the dead parent: a photograph, letters, some toys or a pencil given by the parent. They reported that they looked at these belongings to remember their parents, although it made them sad to see these things.

Emotional Well Being of the Children

Apart from the shock of dealing with parental illness or death, the sheer hardships involved in their daily lives was found to affect the child's emotional health. This was specially true, among the rural respondents, many of whom had reported lower family income and access to services compared to the urban respondents.

Most of the children said they often felt unhappy. More than 50 percent of the children also said that they often felt frustrated and angry. 1/3 of the children said that they had scary dreams and were very afraid in new situations. Many children reported not at all being hopeful for the future.

As a result of this, it was seen that children started thinking like adults very soon. When children were asked to give a wish-list, they rarely spoke of material needs for immediate gratification, as typically children do. Instead they focused on planning for the future, wanting to study well, getting a good job etc.



ALTERNATE CARE-GIVERS AND SUPPORT SYSTEMS

Most parents reported having thought of alternative support systems for the child, in the event of their own death and had taken some action to ensure that the child would not be neglected. In most cases, the chosen support system was within the family: the grandparent, paternal or maternal uncle. The parents had also spoken to these chosen care-givers about their care responsibilities, in the event of their own death. But they had not spoken to the children about these care arrangements.

Most parents reported a preference for within-family supports for the child. They felt that after their death, living with grandparents or uncles and aunts was the best option for the child. Options like putting the child for adoption or in an institution were preferred by just about 20 percent of the parents, that too mostly from the urban areas.

It was found that not many parents, especially in the rural areas, had looked at ways of ensuring property rights and inheritance for the children. Almost 90 percent of the carers reported that they had not thought about the issue, nor made any provision to ensure that the properties were inherited by the children and not usurped by others. Parents in the urban areas were better informed and had taken some action like making a will in favor of the child. However, all parents expressed a need to have more information on this issue and more support and guidance.



CONCLUSIONS AND RECOMMENDATIONS

1. In both rural and urban populations HIV has had an adverse impact on various aspects of the child's life - living arrangements; food security; school attendance and school performance; and changed role in the family, all of which impact on the child's overall well-being and emotional health. Child-centered interventions must, therefore, assess impact in these multiple domains and address them holistically.
2. The drop in household income due to HIV is reported to be affecting the nutrition and health status of children affected by HIV. Hence, interventions with these children need to address income generation at the family level as a priority.
3. Children in both urban and rural settings are currently not recipients of planned disclosure of parents' or their own HIV status. In the absence of counselling and emotional support to work through resultant fears and concerns, they have been found to be experiencing significant trauma. Interventions need to build a high level of counselling services to deal with the life events, anticipatory grief and bereavement that are causing acute distress to children affected by HIV.
4. Despite antiretroviral drugs, there is illness and death and there is a great need for appropriate palliative care, through the different stages of the parental illness. This will allow the child to reconcile with the parent's death, allow parents to suitably plan for the child's future and transfer the responsibilities of care-giving to an alternate care giver of their choice. Advocacy for a strong palliative programme is critical.

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Samraksha started in 1993 as the HIV/AIDS sector of larger development organization, Samuha. Now an independent charitable trust, its goal continues to be to prevent the transmission of HIV and reduce its impact on the people vulnerable to and affected by it. Its current areas of operation are Raichur, Koppal, Gadag, Haveri, Dharwad and Uttara Kannada districts of Karnataka.

Samraksha believes that individuals and communities, if armed with information and power, can and will take responsibility to halt the spread of the epidemic. It believes that it is critical to empower entire communities to act.

It also believes that it is the right of every person living with HIV and AIDS to access care and support services in public, private and social sector. Similarly, it is the responsibility of individuals, communities, private sector and the state to ensure this. Its belief in a prevention to care continuum has led to a range of initiatives across this spectrum.



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