



# Well-Being of the Children Living with HIV Positive Parents

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## ABSTRACT

India, which has the largest number of AIDS orphans in comparison to any country in the world, is facing an accelerating threat from HIV. Despite the availability of anti-retroviral drugs, high rates of adult deaths, the proportion of children being orphaned and made vulnerable by HIV/AIDS remains disproportionately high. Though HIV/AIDS is considered as a serious public health problem, but the disastrous impact it is having on children has not been given adequate attention. The social costs of HIV/AIDS are more acute on children. The availability of psychosocial services to children living with HIV/AIDS remains very limited and inadequate to deal with the long-term psychosocial trauma resulting from caring for dying parents and the grief following their passing away. The children of HIV positive parents, whether they are negative or positive, are denied several fundamental rights. Parents with HIV report feelings of extreme isolation and anxiety concerning their own and their child's health and financial burden of illness. As AIDS saps the lives of young adults, family patterns are reversed. Although children are at a formative and resilient stage of life, policies and programs often overlook them. This paper attempts to address the lack of research and attention given to this important group by discussing the impact of HIV/AIDS on their lives. The paper is based on the study conducted in Delhi. The paper also highlights the need of raising the standard of child care through the development of child care standards which can be applied in a range of care settings including interim institutional care, community based care, foster care etc. The paper also identifies the need to place much more emphasis on what children themselves have to say in research, in policy formulation and the need to have further research on the efficacy of much emphasized community based forms of care.

*Keywords:* HIV/AIDS, well-being, children, parents, HIV positive, Delhi

## INTRODUCTION

June 2011 marked the 30<sup>th</sup> anniversary of the first reports of AIDS in United Nations. HIV/AIDS has moved from being a puzzling disease of unknown origin to a chronic manageable illness in these thirty years. Although we have made substantial advances in prevention, diagnosis and treatment of HIV/AIDS in the past three decades but it is also a hard fact that just in three decades, HIV/AIDS has grown from a health crisis into an economic and developmental crisis.

The world is committed to eradicate HIV and to provide quality care to people living with HIV/AIDS (PLHIV). To reaffirm the commitment, the UN High Level Meeting was held in New

York in June, 2011 on AIDS. The political declaration was made to reach 15 million people with Anti Retro Viral Therapy (ART) by 2015, eradication of HIV transmission from mother to child, halving HIV transmission through injecting drug use and through sexual transmission among young people across countries (General Assembly of United Nations, 2010)<sup>2</sup>.

HIV/AIDS is not just a health problem but a social problem too. The impact of HIV/AIDS on families and children is complex and multidimensional. Its impact is often highlighted as 'orphaning of generations' and referred to as the third wave of the epidemic – following infections and AIDS deaths. Orphaning is not the only way that children may be affected by HIV/AIDS, others are affected by HIV/AIDS include those who have ill parent/s, are in poor households are discriminated against because the HIV status of the family member/s or who have HIV infections themselves.

Though the HIV epidemic that the world faces today is not the same as when it peaked in 1996. The number of people living with HIV globally is at 33.4 million currently and although 2.7 million people became newly infected with HIV in 2008, the good news is that this is a decrease by 17% over the last eight years (UNICEF, 2006)<sup>9</sup>.

In the past three decades, the HIV/AIDS epidemic has seen many transitions. The initial years of the epidemic kept shifting from one high-risk group to other. Initially emphasis was given to targeted interventions, but later, as the number of women victims of HIV increased, there was a shift to society at large. It has taken many years to understand the devastating effect HIV/AIDS has on children's lives, and recently, there is a growing concern over the number of orphans it has created.

**HIV/AIDS in India.** The initial cases of HIV/AIDS in India were reported among commercial sex workers in Mumbai and Chennai and injecting drug users in the north-eastern State of Manipur in 1986 (National AIDS Control and Prevention Policy, 2003)<sup>7</sup>. An estimated 2.27 million people were living with HIV in 2008 (Annual Report, Department of AIDS Control, 2009-10). India carries the largest burden of HIV after South Africa and Nigeria. The epidemic in India is showing a declining trend overall, HIV prevalence among adult population in 2007 was 0.34 percent and in 2008 was 0.29 percent. Women account for 39 percent of PLHIV while children account for 3.8% (Country Progress Report, UNGASS, 2010)<sup>2</sup>.

HIV/AIDS is not a single epidemic, but rather there are multiple epidemics that evolved over time, with differing origins, transmission patterns and impacts on regions and population groups. HIV prevalence in the general population is disproportionately distributed across states within India and also across districts within states (IIPS and Macro International, 2007)<sup>6</sup>.

**Status of HIV/AIDS in Delhi.** The first case of HIV/AIDS in Delhi was detected in 1988. Delhi is a low prevalence state with a prevalence rate of 0.25% in general population. There are four B category (moderate prevalence) districts. The estimated number of PLHIV in Delhi is 51,818 (Delhi State AIDS Control Society, 2010)<sup>3</sup>. Delhi is a highly vulnerable State because of large number of most at risk population like migrant population, female sex workers (FSW) Men having Sex with Men (MSM) and Injecting Drug User (IDU). Integrated Counseling and Testing Centre

(ICTC) data shows HIV prevalence in 15-25 years is 1.94% (8.8 times the general population). HIV prevalence in Sexually Transmitted Infections (STI) clinic attendees is 5.2%. There is high incidence of STI in MSMs (57%) in Delhi. It is the highest in the country (Delhi State AIDS Control Society, 2010)<sup>3</sup>.

**Causes of HIV infection in children.** The most common cause of HIV infection in children is from parent to child transmission (PTCT) during pregnancy/ at the time of birth or during breast feeding. Children, especially at birth may get exposed to HIV infection, that is, they may come into contact with HIV infected blood and blood products or unsterilized needles or medical equipments and may become HIV positive. Sexual abuse, or rape or other non consensual sexual activities may expose the children to HIV infection if the abuser himself is HIV positive. Genital mutilation or any cut in the vaginal area can also be the potential source for passing the HIV virus. Donor insemination, womb surrogacy and wet nursing could also be the risk factors in HIV transmission in children.

Infected children differ from infected adults in several ways. Firstly, the disease progresses much more rapidly in children, secondly children have higher viral loads than those usually seen in adults, thirdly children have recurrent invasive bacterial infections more often and finally, opportunistic infections often present as primary diseases with a more aggressive course because of lack of prior immunity. The widespread prevalence of malnutrition makes Indian children more vulnerable to AIDS than their counter parts in developed world. This is because malnutrition reduces the "window period" between HIV infection and full blown AIDS by four to ten times i.e. from the usual time lag of 8-10 years to one or two years. Infected infants born to infected mothers will become orphaned early in childhood (as their parents die of AIDS) and face all the social consequences.

Although significant gains has been made in acquiring knowledge about HIV/AIDS, but very little progress has been made on the disastrous impact it is having on children worldwide in general and in India in particular. Most of the behavioral studies have been conducted on adults. Many issues related to HIV/AIDS children still need exploration. Researches on adults cannot be extrapolated directly to children because children are affected by the disease in ways different from adults. The children of different age have different cognitive, physical, emotional and social abilities. Children with HIV often have the same infections as children without HIV, but the infections are more recurrent, severe and persistent. HIV/AIDS compromises children's rights to survival, education and health care. It jeopardizes the children's right to protection from discrimination and abuse and sexual exploitation, trafficking and child labor. It robs children of their rights to grow up in a family environment and to develop to their fullest potential.

## METHODOLOGY

Keeping these points in mind, it was considered important to conduct a study on the well-being of children living with HIV/AIDS in families. The objectives of the study were to examine the profile of children living with HIV/AIDS in families, to gain insights into children's understanding of the illness and its impact on their lives to investigate patterns of care available to children living HIV/AIDS, to identify the constraints in the effective delivery of services to children living with HIV/AIDS in families and to develop cost effective paradigm/system to provide care and support to children living with HIV/AIDS

Thirty children living with HIV/AIDS in families who were in the age group of 07-14 years were selected through the NGOs working for them. Purposive sampling method was adopted to select the key respondents among the children. The selection of these families was dependent upon their willingness to participate in the study. Parents, grandparents, doctors and community level workers were also the part of the sample of caregivers.

The study was an exploratory research that focused on the situation of children living with HIV/AIDS and requires both a qualitative and a quantitative approach. The attempt was to look at the care of children living within families. Multiple case study design was employed to get in depth information of the children and their contexts.

Interview guides, observations, narratives of parents and children, Subjective Wellbeing Inventory for mothers and Self Perception profile for children were used as tools for data collection.

**Ethical concerns.** Oral consent was taken from the parents during theme based group discussions and in other workshops. Families were contacted on phone before having a dialogue with them at their residence and the written consent was taken from them at the time of interaction. They were also assured of the confidentiality.

## RESULTS AND DISCUSSION

**Familial environment.** Table 1 on the next page shows the demographic profile of families living with HIV/AIDS. Sixty percent of the families did not have surviving male adult partner. Infection entered in the family through unsafe sex with multiple partners by the male member of the family. All families reported severe marital quarrels and abusive nature of the male member of the family. A total of twenty four mothers were HIV positive and all were alive.

The characteristic features of the families living with HIV/AIDS were marital discord, poor communication among couples, domestic violence, alcoholism, dominance by/of male spouses, temporary non disclosure of the disease to wives, diagnosis of HIV infection in men through some dreadful disease like tuberculosis etc. There was rejection by the relatives, delayed HIV testing of wives and children and non-adherence to ART were some of the other defining features of the families living with HIV/AIDS.

The following case profiles depict the lives of women before and after the diagnosis of HIV infection.

*“Mera aadmi band master tha. Shadiyon mai 1-1.5 lakh kama leta tha. Hamara achchha kam tha. Hum ikkaththe rehethe the. Vo pita tha aur uska kisi se chakkar bhi tha. Mai ye sab jaanti thi aur gussa bhi karti thi. Vo uske baren mai ek baat bhi nahin sunta tha, mujhh se ladta tha aur mujhhe marta tha. Talak dene ki dhamki deta tha. Shayad mere susral wale uski bimari ke baren mai jaante the, per unhone mujhhe eske baren mai kuchh nahin bataya. Vo bimar hone par paas ki dawai ki dukan se dawai leta tha. Ek bar jab ghar mai koi nahin tha to uski chhati mai jor ka dard utha. Usne mujhhe doctor ka kagaz diya aur dawai wale se dawai lane ko kaha. Dawai wale ne mujhhe dawai dene eke saath kuchh ulti seedhi batae bhi batai. Mujhhe bada gussa aaya. Maine ghar aa kar dawai wale ki gandi baton ke baren mai apne aadmi ko kaha. Vo kuchh nahin bola chup chap suntan raha. Bad mai jab usko TB asptaal mai dakhil karaya to uski HIV ki jaanch hui.*

*Usme bimari nikali. Mujhhe 2005 mai uski bimari ka pata pada. Meri aur bachhon ki bhi jaanch hui. Mere mai bhi bimari nikli. Bachho mai bimari nahin thi. Us time mujhhe es bimari ke baren mai kuchh pata nahin tha. Jab doctor ne bataya ki isko HIV hai, to mai khush hui ki chalo TB to nahin hai. HIV ka ilaz to hum kara lenge. Baad mai pata pada ki ye bimari to TB se bhi khatarnak aur lailaaz hai. TB asptaal ke doctor ne bhi mujhhe vahi salah di jo dawai wale dukandaar ne di thi. Bimari ke ilaaz mai hum ne apni dukan bech di aur kiraye par dukan le kar kam karne lage. Kuchh time baad usne bimar rehene ke karan uska dukan par jana band ho gaya. Ghar mai paiso ki bahut hi tangi aa gai. Ek time aisa aaya ki ghar mai khane ko kuchhe nahin tha, bas peene ke liye pani tha. Kuchh time uske dostoon ne anaz aur subj di. Mere bhi ma bap ne jitna vo kar sakete the, madad ki. Susral walo ne kuchhe nahin kiya. Bimari pata padne par hume pehli manjil par bhej diya. Koi hum se baat tak nahin karta tha, bas sanstha ke log aate the. Mujhhe apne bachhon ko bimari aur paison ki tangi ki vajah se hostel bhejna pada. Mere susral walo ne sanstha ke logo ke vyavhar ko dekh kar apne tour tarike badle. Mera aadmi 2007 mai chala gaya. Us time vo 39 saal ka tha.”*

*Translation:* My husband was a band master. He used to earn up to one and a half lacs during marriage season. We had our own shop. We had a flourishing business. We used to live in joint family. My husband was an alcoholic and had an extra marital affair with a girl near his home. I knew of his relationship and objected to it often. He used to fight with me and hit me if I said anything against that relationship. He used to threaten me with divorce. I think, my in laws knew his illness, but they hid it from me. My husband used to get medicines from a nearby shop. Once there was nobody at home and he had severe pain in his chest. He gave me the paper of doctor’s prescription and asked me to bring the medicines from the chemist shop. The chemist gave me the medicines and also told me some precautionary advice to follow to prevent myself from infection. I got infuriated at him and told my husband about chemist’s immoral behavior. My husband did not utter a word. Later, he was admitted to a tuberculosis (TB) hospital. There they conducted HIV test on him. I came to know of his positive status in 2005. The same year, I was tested and found positive. Luckily my daughters were found negative. At that time I was absolutely unaware of HIV/AIDS. When the doctor disclosed his HIV status, I felt relaxed. I said, “It does not matter, if he has HIV/AIDS. We can get its treatment done, but he should not have TB”. Later, I came to know that it is much dangerous than TB and is incurable. The doctor also gave me the same piece of advice that the chemist gave me. We had to sell the shop to bear my husband’s treatment expenses and shifted our business to a rented shop. After few years, he stopped earning because of his illness. We were pushed into utter poverty. There was a time when there was nothing to eat except water to drink. For a few months, his friends helped us by giving wheat, vegetables etc. My parents also helped us as much as they could. My in laws did not help us at all. When HIV infection was diagnosed, we were asked to shift on to first floor. Nobody used to talk to us. The only people who used to visit our home were from various NGOs working in the field of HIV/AIDS. I had to keep my daughters in a residential institution because of my husband’s illness and poverty. My in laws stopped discrimination after watching the behavior of NGO people. My husband died of AIDS in 2007. He was 39 years old.

**Table I Demographic profile of the families at the time of data collection**

| <b>Sample Characteristics</b> | <b>Categories</b> | <b>Number</b> |
|-------------------------------|-------------------|---------------|
| <b>Mean age of parents</b>    | Fathers           | 37.3 yrs.     |

|   |                       |           |
|---|-----------------------|-----------|
|   | Mother                | 32.7 yrs. |
| <b>Total number of children</b>                   |                       | 72        |
| <b>Age range of children</b>                      |                       | 4-23 yrs. |
| <b>Sex of children</b>                            | Boys                  | 37        |
|   | Girls                 | 35        |
| <b>HIV status of children</b>                     | HIV positive children | 8         |
|   | Affected children     | 23        |
| <b>Children on Anti-Retro-viral therapy (ART)</b> |                       | 6         |
| <b>Parental Status</b>                            | Alive fathers         | 12        |
|   | Alive mothers         | 30        |
|   | Dead fathers          | 18        |
|   | Dead mothers          | 0         |
| <b>Parental HIV Status</b>                        | HIV positive fathers  | 29        |
|   | HIV positive mothers  | 24        |
| <b>ART Status</b>                                 | Alive fathers on ART  | 11        |
|   | Alive mothers on ART  | 19        |
| <b>Income group</b>                               | Families              | Lower SES |

**Impact of HIV/AIDS on family dynamics.** Many families had to change their residence in search of treatment of the disease. All families reported experiences of stigma and discrimination at the hands of their closest kith and kin after the disclosure of HIV infections. Frequent outbreak of opportunistic infections in the family affected the schooling of the children. Their school attendance became irregular and their performance dropped. The children were shifted from private to government schools in five families. Women had to devote much of their time in taking care of their sick husband and children even though they themselves remained sick leading to time poverty and incurring opportunity cost and empowerment cost. The families lived under the environment of stress, anxiety and agony after the diagnosis of HIV/AIDS. A HIV positive woman with HIV negative husband reported that her husband blamed her for bringing the disease into the home. He called/labeled her ‘characterless’. The women living with HIV/AIDS also incurred high emotional cost.

**Impact of HIV/AIDS on the employment.** The education level of the parents varied from illiteracy to graduation. The occupation of the fathers of children irrespective of their survival status varied considerably. They were driver, shopkeepers, Out Reach Worker (ORW), painter, band master, priest etc. All families reported that they were economically self sufficient and stable

before the diagnosis of the disease. Increased medical expenditure on health, frequent illnesses and loss of job/business changed their socio economic status to very poor families. Sixteen women were working as volunteers in Non Governmental Organizations (NGOs) working for people living with HIV/AIDS /domestic or patient care help, helper in NGO or as Out Reach Worker.

The research findings of the present study highlighted the substantial and every day practical challenges that were faced by the families living with HIV/AIDS. Worsened poverty due to HIV/AIDS and ill health remained as key challenges after the diagnosis of HIV infection. They were shunned by potential employers due to frequent opportunistic infections and consequent absenteeism. They also reported that their ill-health made it harder to find work because they were not able to commit to regular work attendance before 2004 when ART was not freely distributed by the government.

**Access to health care.** Seventeen fathers were on ART, twelve died before the initiation of ART and one was HIV negative. All families who were on ART were procuring medicines from the government hospitals. The children were taken to the hospital for general health checkups and to collect the ARV medicines.

**Discussion on parental health.** Eighty percent of the families did not discuss parental health with the children. Rest of the parents discussed about their and children's health but without mentioning HIV.

**Disclosure of HIV status.** Older children who were in the age group of 11-14 years knew the HIV positive status of the family. However, there was no formal disclosure of HIV status to them. The younger children knew the name of the disease. They were not aware of the incurable nature of the disease. They had the feeling that they or their parents were sick with some serious illness. None of the families had disclosed their HIV status in their neighborhood and in their children's school. Paternal and maternal members of all families (except one paternal) knew the HIV positive status of the families.

**Linkage with NGOs.** All families were linked to more than one NGO working in the field of HIV/AIDS. The families were grateful to the NGOs. The families felt that they gained knowledge about HIV/AIDS, got psychosocial, financial, medical, nutritional and spiritual support by attending meetings of NGOs. They also felt that they have become bold, confident and empowered.

**Coping with bereavement.** The women tried to keep themselves and their children busy to avoid thinking about their dead husband/father. They also reported that the discourses on spirituality helped them tremendously.

**Parental worries about children.** All mothers reported that large part of their day was spent in worrying about their children. The worries were related to care choices and wellbeing and the future of their HIV positive children after their death.

**Future plans.** Sixty percent families saved money for future through various modes. All the families were members of Self Help Group (SHG) facilitated by the NGO.

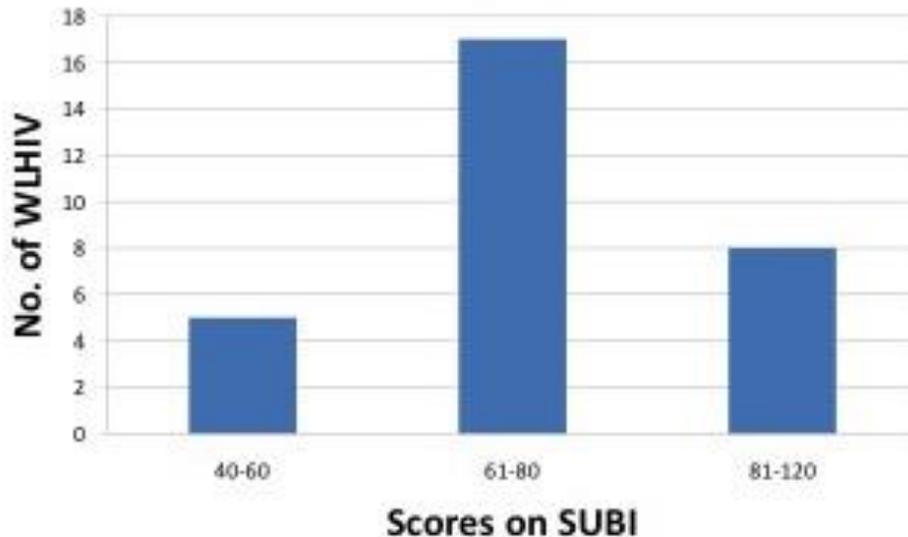
**Succession plan.** Most parent(s) (21) reported that they would like to bring up their children on their own. They wished their children to stay with them and to grow up in their care. They also reported that the fulfillment of their wish was dependent on their sound health and financial status. The families had no concrete succession plan for their children in place but they had given a thought to it.

**Positive changes post diagnosis.** Most sero positive families (21) reported that after the diagnosis of the HIV infection their husbands' indulgence in high risk behaviors such as maintaining sexual relations with multiple partners, intake of alcohol reduced and they started taking care of the family therefore marital life improved to a great extent.

**Feelings of well being in women with living with HIV/AIDS.** Despite the increasing incidence of HIV/AIDS in women, there is a serious lack of information about women's quality of life. An attempt was made in the study to find out the feelings of well-being of women living with HIV/AIDS by administering the Subjective Well-Being Inventory (SUBI) developed by Rup Nagpal and Helmet Sell. The Student t test of significance was applied to ascertain the difference in the feelings of well being of women living with HIV (WLHIV) on the basis of their marital status (HIV widows and WLHIV with husband), HIV status, ART status, age, education and occupation.

The following figure shows the scores of women on SUBI:

**Distribution of Scores of WLHIV on SUBI**



The factorial scores showed that women living with HIV/AIDS were trying to adjust with their life situations. The narratives of women indicate that they were trying to cope with the adversities and in this the NGOs and governmental efforts seem to be bearing positive results. It may be inferred that some women were experiencing difficulties in terms of a happy living but quite a few also enjoyed a good sense of well-being. The t test revealed statistically significant difference (p value 0.02 at 0.05 CI) in the scores of HIV positive and affected women on positive items. It was found that HIV negative women were better off than HIV positive women. They had HIV negative children and were not also much worried about their health. They were better educated and four

were working. This shows that they have begun to feel that their life is functioning somewhat smoothly and joyfully, developing satisfaction with their standard of living, personality strength to master critical or unexpected situations, deriving feelings of subjective well being from values of spiritual quality, perceived wider family (maternal family) as supportive and social environment beyond family as supportive. This may be because of the positive role played by the NGOs in the lives of PLHIV and also because of non disclosure of family's HIV status to the wider social network i.e. school, neighborhood etc. There was significant difference (p value 0.05 at 0.05 CI) between the mean positive scores of who had studied up to primary levels and those who studied up to senior secondary levels. This showed that WLHIV who studied up to senior secondary levels were better able to manage with HIV infection, had better jobs, four were HIV negative widows with HIV affected not infected children. Hence, they had better feelings of subjective well-being in comparison to those who have studied up to primary level.

The p values for mean total scores and mean positive scores and mean negative scores were not statistically significant for ART status, age, marital status and occupation.

**Expectations from the NGOs and the government.** WLHIV had many expectations from the NGOs working for PLHIV depending upon their immediate circumstances. The government has fulfilled some of their expectations.

**Lives of Children Living with HIV/AIDS in Families** The mode of transmission of HIV infection in all children was from parent to child.

**Impact of HIV/AIDS on children's lives.** The most major impact of HIV on children's lives was the death of the father. Other impacts were financial crisis, mother headed single parent families, and absence of adults in the family decrease in school attendance and school performance and deterioration in the quality of food taken at home.

HIV-positive parents caring for HIV-positive children demonstrated good knowledge of HIV, and tried to provide adequate nutrition for/to the HIV-positive children in their care but caring for such children was not without challenges.

**Community participation.** The families had not revealed their HIV status in the neighborhood. All children had friends in the neighborhood except three. Fifty percent children reported that they initially had difficulty in making friends. Self stigma could be one of the reasons for having difficulty in making friends.

**Children's worries and their coping mechanisms.** The children had worries related to studies, school tests, parental or their own health. To stop worrying children watched television, tried to sleep or played with friends.

**Behavioral issues in children.** All families reported one or more behavioral issues like aggression, thumb sucking, stealing, sleep disturbances, enuresis, pica etc. in their children, which were the cause of parental worries.

**Children in school.** All children (29) under the study were going to school except one. None of the families have disclosed their own or the child's HIV status in the school. All children had friends in the school and they helped them as and when their help was required. All parents emphasized on the academic performance of their wards and asked them to work hard. Emphasis on academic achievement was more on HIV affected children. The children had varied career ambitions, which were influenced by their circumstances, desires and experiences.

**Self concept of children living with HIV/AIDS in families.** Self perception and self presentation are relatively unexplored areas of children with HIV (CLHIV), though of practical concern to the caregiver as the psychological problems are connected with the child's favorable or unfavorable perception of self and his/her perception of relationship with the significant others. The child's perceived self competence was assessed using the scores obtained on the 'What Am I Like' schedule. Mean scores for each child were calculated in the six domains namely Scholastic Competence (SC), Social Acceptance (SA), Athletic Competence (AC), Physical Appearance (PA), Behavioral Conduct (BC) and Global Self Worth (GSW). Subscale means and standard deviations were also calculated. Table II shows the gender differences on Self Perception Profile.

**Table II Gender Differences Among Children in the Sub Domains of Self Perception Profile**

| <b>Sex</b>             | <b>SC</b>  | <b>SA</b>  | <b>AC</b>  | <b>PA</b>  | <b>BC</b>  | <b>GSW</b> |
|------------------------|------------|------------|------------|------------|------------|------------|
| <b>Boys (N=17)</b>     | 2.1 (0.79) | 2.8 (0.60) | 2.5 (0.54) | 3.1 (0.45) | 2.8 (0.29) | 2.9 (0.53) |
| <b>Girls (N=13)</b>    | 2.8 (0.67) | 3.1 (0.45) | 2.6 (0.54) | 3.3 (0.50) | 2.9 (0.56) | 3.2 (0.47) |
| <b><i>p values</i></b> | 0.03       | 0.18       | 0.52       | 0.20       | 0.56       | 0.12       |

*Note: p values <0.05, in parentheses (SD).*

There were significant differences in the scores of girls and boys (p value 0.03 at 0.05 CI) in the sub domain of Scholastic Competence. The girls scored higher in the sub domain of Scholastic Competence than boys. This may be because of the fact that more boys were HIV positive than girls. Out of seven children, five boys were HIV positive. HIV positive status of the child impacted his/her education negatively because of HIV associated stress and illnesses. Boys off and on bunked their private tuition classes. Truancy on the part of boys was reported by their parent(s). There was statistically significant difference in the scores of HIV affected and HIV positive children in the sub domains of scholastic competence (p value 0.05 at 0.05 CI) and global self worth (p value 0.01 at 0.05 CI). The HIV affected children were better in Scholastic Competence and Global Self Worth than HIV positive children. The reasons for this may be stress and illnesses associated with HIV infection. Emphasis on academic performance was not much on HIV positive children. Besides social stigma, HIV positive children also had self-stigma, which prevented them from interacting with others. They also reported difficulty in making friends. All this might have led to low scores on the sub domain of global self worth. Table III shows the distribution of means of HIV affected and HIV positive children on Self Perception Profile:

**Table III** *Distribution of Means of HIV affected and HIV Positive CLF on Self Perception*

| <i>Profile</i>               |    |               |               |                |               |               |               |  |
|------------------------------|----|---------------|---------------|----------------|---------------|---------------|---------------|--|
| HIV status                   | N  | SC            | SA            | AC             | PA            | BC            | GSW           |  |
| <b>HIV affected children</b> | 23 | 2.6<br>(0.68) | 3.0<br>(0.51) | 2.51<br>(0.53) | 3.2<br>(0.42) | 2.9<br>(0.37) | 3.2<br>(0.48) |  |
| <b>HIV positive children</b> | 07 | 1.9<br>(0.96) | 2.7<br>(0.65) | 2.5<br>(0.61)  | 2.9<br>(0.60) | 2.7<br>(0.56) | 2.6<br>(0.43) |  |
| <i>p-values</i>              |    | 0.05          | 0.21          | 0.96           | 0.12          | 0.24          | 0.01          |  |

*Note: p value < 0.05, in parentheses (SD).*

There was no significant difference in the scores of children in the sub domains of the test with respect to age and orphan-hood signifying that age and orphan-hood did not affect self concept of children.

**Knowledge about HIV.** All children had heard of HIV. All children knew about the three causes of its transmission and only 8 children knew about all the modes of HIV transmission. All children knew the precautions to be taken while undergoing blood transfusion. None of the schools organized any awareness campaigns on HIV.

**Constraints in the Effective Delivery of Services to Children Living with HIV/AIDS as perceived by the Caregivers and Children**

The constraints in the effective delivery of services to children living with HIV/AIDS can be classified into 3 levels. These are constraints at household level/ institutional level, at health services delivery level and environmental and contextual constraints.

**Constraints at household/institutional level.** Diagnosis of HIV/AIDS in the family and death of one or both parents not only changed the parenting pattern but also redefined the concept of childhood for the children as well as parents living with HIV/AIDS. All these factors affected their optimal development and also led to behavioral issues. HIV/AIDS restricted the alternative care choices for children who cannot live with their parents.

Irregular parental visits, irregular funding, high attrition rate of NGO and institutional workers, increased work load, maintenance of many records by the institutional personnel, low levels of education of institutional workers were the other constraints in the effective delivery of services to CLHIV in residential institutions. Resource crunch was the hardest constraint faced by the residential institutions. It even led to the closure of residential facilities for the children living with HIV/AIDS.

**Constraints at health services delivery level.** Non availability of medicines and psycho-social support services for care givers and children, long queues in hospitals, non cooperation of paramedics of departments other than ART center, specific timings of laboratory tests, contractual nature and low wages of ICTC and ART center’s staff were the other constraints in the effective delivery of services to the families and to CLHIV.

**Environmental and contextual constraints.** Disturbed family environment, stigma and discrimination from the relatives, inadequate livelihood support services, ignorance about social welfare schemes, non possession of valuable documents like voter identity card, worsened poverty affected the care giving paradigms for CLHIV in families.

### **Caregiving Paradigms for Children Living with HIV/AIDS.**

**Caregiving by families.** Living in home with one or both parents was a blessing/privilege for the children living with HIV/AIDS. The care giving tasks in times of ill health like taking the child to hospital, NGO, home based care were performed by the whole family where both the parents were HIV positive and mostly by the mothers in case of single parent mother headed HIV affected families. The cost of food in case of familial children was primarily borne by the parents, relatives from maternal side, NGOs and the government (in case of families who were having ration card/BPL card). Some families had Life Insurance policies of various denominations for their HIV affected children.

**Support from relatives, neighbors, friends and spirituality.** Maternal relatives of most PLHIV supported them financially or through provision of other services like food grains, vegetables, care giving to children in times of emergency, providing accommodation in case of single mothers, accompanying them for hospital visits etc. Neighbors also helped PLHIV. Friends in the school/neighborhood were the source of psycho-social support for children living with HIV/AIDS. Helpful nature of the teacher encouraged children to attend school regularly. Discourses on spirituality helped PLHIV and children to cope with bereavement, develop confidence and move forward in life with courage.

**Provision of care and support services by NGOs to families living with HIV/AIDS.** Parental linkage with the NGOs working in the field of HIV/AIDS had a therapeutic effect not only on the well being of the parents but also on the whole family. It also helped in reducing many stressors related to HIV/AIDS, thereby enhancing their mental health, effective parenting strategies and fulfillment of child rights.

**Provision of care and support services by the government to PLHIV and CLHIV.** The health care facilities like diagnosis and treatment of opportunistic infections including TB, HIV testing services etc. were provided by the government free of cost. Regular health checkups of the children were done in hospitals. Those children who were on first line ART were availing it from the government hospitals which was available free of cost to all eligible CLHIV and those who were not on ART also got their routine health checkups done once in a month and laboratory tests like CD<sub>4</sub> count etc. done biannually. Nutritional supplements in the form of multi-vitamins were provided to PLHIV. Some PLHIV were integrated as 'Out Reach workers' for positive prevention into various training programs and their capacities were strengthened for positive prevention and care, support and treatment activities. Free education was provided by the government to all children studying in government schools up to 14 years of age. The children were also given stationery, school bag, uniform, scholarships, mid day meal etc. to continue their education. Those PLHIV who were having the birth certificate of their girl child or school leaving certificate were eligible to avail conditional cash transfer scheme '*ladli*' initiated by the government for girls to continue their education up to senior secondary level and postponement of their marriage until 18

years of age. The government at a highly subsidized rate provided food grains and other items to families below poverty line who were having ration card/BPL card.

## CONCLUSIONS

The HIV/AIDS infection caused sufferings and deaths in the families and pain and angst in lives of children under study. HIV had an adverse impact on various aspects of the stability of child's life - living arrangements; food security; school attendance and school performance; and changed role in the family, all of which impacted the child's overall well-being and emotional health.

It seemed that the children were told not to discuss the HIV status of the family with anybody. This forced secrecy can be a great burden on children because they have to control what they say, what they do and how they express what they feel. Giving children the opportunity to talk about their feelings and experiences with other children may be with

other children allows them to realize that they are not alone and helps to build their self confidence. Such initiatives are often not identified, or strategically integrated into the psychosocial support programs for them.

Complete drain of physical, emotional, material and financial resources of the family along with isolation and rejection by the relatives was reported by all families. Illnesses in the family, parental/spousal deaths, stigma, social isolation from relatives, and the financial difficulties were the most traumatic experiences reported by the children and surviving parents living with HIV/AIDS in the present study. All HIV positive children had experienced discrimination from immediate kith and kin and married HIV negative siblings. The discrimination was less stark in the case of single parent HIV affected family. The following figure shows the interlink between HIV infection, stigma, care options and self worth of the child which was found from the study:

Evident from the study was the critical importance of support for the family in maintaining intactness. The Indian family characterized by collectivism and "familism (Anandalakshmy, 1984)<sup>1</sup> shows a decline in the same when illness like HIV strikes. The extended family offered very little in terms of support to the suffering family unit. The PLHIV found their maternal family members more helpful than paternal family members.

All parent(s) wished to fulfill parental responsibilities towards their children but it was dependent on their sound health and good economic conditions. The children were seen with great hope by HIV positive parents. Global research shows that a loss of parental care is often caused by poverty or irregular incomes and conflict, violence and abuse in the home (EveryChild 2009)<sup>4</sup>. Most families had no concrete succession plan for their children. Some of the maternal grandparents of affected children of single mothers showed their willingness to keep them, if they were provided with the monetary help as were not economically well off to bear the expenses. Financial assistance to grandparents may help in averting placement of at least HIV affected children in residential institutions to an extent. None of the families had registered 'will' in the name of their children.

NGOs emerged as powerful force in the effort not only to contain the epidemic but also in relieving the sufferings and deprivations of PLHIV but were facing hard times due to global economic recession. The provisions initiated by the government also helped PLHIV in mitigating the impact of HIV/AIDS to a great extent. Provision of free ART to all the eligible PLHIV was the biggest game changer besides other provisions.

HIV infection was vertically transmitted (parent to child transmission) in all children. Quality of life of those HIV positive children who were on ART improved tremendously because of the availability of anti retroviral drugs. Intake of ARV drugs and nutritious food tremendously reduced the incidences of opportunistic infections in HIV positive children. The children clearly distinguished their quality of life when their parents were alive and well, when they became sick, and when they eventually died.

The children faced wide range of emotionally traumatic events like losses, crises, difficulties and isolation, which might have triggered the development of behavioral issues in children. They tried to come to terms with such life changing situations.

The psychosocial distress and well-being co-existed in children. Older and HIV affected children showed greater signs of strength than younger and HIV positive children. Though psychosocial distress was widespread among them in the study but they also developed their own constructive coping skills, and demonstrated a degree of confidence in their ability to manage life stressors. Peer relationships emerged as an important source of social support and coping, as most of the children enjoyed the time they spent with friends. Informal psychosocial support, provided by peers, family members and teachers helped in relieving psychological distress and maintaining the mental health. Many of their wounds were healed but many were left unhealed.

Children are not a passive, voiceless and powerless target group to be aided, but are capable actors and important resources to be engaged in response to AIDS. Children should not be mere receivers of programs but, should be the active participants in the development and execution of programs related to them. Active involvement of children in care initiatives will not only build children's own sense of self-esteem and efficacy and cultivate skills, which they can use in future but also make them see that they can make a difference and are wanted. This will increase their willingness to avoid behaviors that increase their own risk of acquiring HIV infection (Family Health International, 2001)<sup>5</sup>.

## RECOMMENDATIONS

It was evident from the findings that the family should be considered as the unit of intervention to mitigate the consequences of HIV/AIDS on children and adolescents. To support families and children living with HIV/AIDS, it is important to understand their problems, resources and their coping strategies. There is a need to recognize that AIDS affected families do not comprise a homogeneous category, they involve many variations with respect to family types, poverty level, education, household structure, stage of illness progression, dependency ratios, social status, and access to assets. It signifies that a mixture of approaches will be more appropriate and successful than a single approach.

It is very important to explore, identify and strengthen the intra and inter-personal resources of women for coping with the impact of HIV/AIDS infection. Positive feelings about life can be considered as intra-personal resources. Psychosocial support should be provided for children living with HIV/AIDS. Grief counseling should be incorporated in the programs. Issues related to death should be dealt with children keeping in mind the age and cognitive maturity and their

understanding of the death.

There is a need to create awareness about various governmental schemes for poor people, women and children. The government should open more *anganwadis* to cater to the needs of the families living with HIV/AIDS. This will not only provide supplementary nutrition to children, pregnant and lactating mothers but will also reduce the care giving burden of mothers. The program should be extended to include children above six years of age and their parents irrespective of their fertility status.

Programs need to take a holistic approach that meets the health, nutritional, psychosocial, educational and economic needs of children and families. Programs should involve several sectors and promote collaboration, networking and referrals between government and NGOs. Programs should also wherever possible, be integrated into existing services and should also involve all sectors and to provide effective coordination of actions to meet the needs of children.

All programming should center on the best interests of the child, which also implies encouraging the child to contribute to his/her well-being wherever possible and not just expect all his needs to be met by the service providers. It is important to focus on all vulnerable families, rather than only orphans or families and children living with HIV/AIDS. Reliance on HIV status may make PLHIV reluctant in using the services because of the fear of disclosure of HIV status and associated stigma and discrimination. Families and NGOs should be encouraged to use inclusive approach with special focus on families living with HIV/AIDS.

The best interests of the child are served when the child is at the center of a caring family, within a supportive community, surrounded by a protective state and the solidarity of the international community. The following are some of the recommendations to enhance the wellbeing of children living with HIV/AIDS in families:

‘Life Skills education’ classes should be organized for children who are at primary levels of education. These skills should be merged with academic skills in a way, which is appropriate to the age and comprehension level of the children. There is a need to update the knowledge of HIV affected families about HIV/AIDS. Clear and candid information about how HIV is transmitted and how it is not transmitted is to be given to people including members of the families living with HIV/AIDS. Child care centers with flexible timings, opening at night to avoid placing children in the institutions.

Capacity building and training of parents, healthcare workers, counselors, outreach workers from NGOs and formation and strengthening of support groups for children, adolescents, and parents are important for hassle free disclosure and to overcome the after effects of disclosure. There should be child friendly services available in the hospitals.

With combined and sustained efforts we can make the world a safer place for children to live in with dignity. Through committed partnerships and collaborations millions of children and adolescents will have a chance of a better future.

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