

The Plight of Children Growing Up in HIV Afflicted Families in Delhi

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Abstract:

India seems to be a low HIV prevalence country in percentages on the global map but the virus in absolute numbers has affected and changed the lives of millions of people across the country. With HIV and AIDS infecting any one person in a family, the child in the family becomes vulnerable in many ways. The current study gives a depiction of the situation of children growing up in HIV afflicted families where at least one parent is affected by HIV.

In depth Interviews were conducted with 50 parents (mother/ father). The respondents have provided information regarding the impact of HIV status of parent/s on children's education, healthcare, recreation and social interactions of the child. The study also highlights the barriers and obstacles encountered in the overall development of child as stated by their parent/s.

The findings show that, along with the responsibility to earn to run the households, they also have to struggle with their health. They learn to cope up with stigma and discrimination, paucity of funds and parenting children who have witnessed the death of their one parent. The findings also bring into light various psychological and social needs of these children which remain unmet because of this illness in the family.

In conclusion, the current study brings out the impact of HIV on all family members to be both disturbing and alarming. Thus, the paper suggests some possible ways to address the issues, needs and challenges faced by children growing up in families affected by HIV.

Key Words: Children, HIV/AIDS, Impact on children, HIV afflicted families

In India there are an estimated 20.89 lakh people currently living with HIV and AIDS. Reportedly, India has a total adult HIV prevalence of 0.27 per cent for the year 2011 (NACO, 2013). India appears to be a low HIV prevalence country in percentages but the virus has in absolute numbers affected and changed the lives of millions of people across the country. According to NACO (2013), children less than 15 years of age account for 7.0 per cent (1.45 lakh) of all HIV infections. Given the enormity of the ailment even after three decades of it being reported, it becomes even more critical to look into its impact upon the family, esp. on the children, who aptly are considered to be the future of a Nation.

HIV and AIDS is one of the leading causes of death among children. Recent data suggest that new infections with the HIV among children are decreasing because of availability of services preventing transmission of the virus from mother to child during pregnancy, labour, delivery or breast feeding.

With HIV and AIDS infecting any one person in a family, the child in the family becomes vulnerable in many ways. The illness of the parent/s affects the child irrespective of his/her own sero-status in

multiple ways. It is worrying for a child if a parent is unwell or is suffering from an illness, more so if they come to know it is terminal as is the case with AIDS. One problem at home triggers another, creating a further burden which is usually difficult for children to cope. Difficult situations at home create unnecessary stress for the children. It is devastating for their emotional and psychological growth. When a parent finds out that he or she is infected with HIV, his own suffering and trauma usually engage him to an extent that he may not be able to perform normal parenting roles. The impact on the child is both immediate and long term. The consequent deprivation is immediately psychological-emotional and then developmental in the long run.

The situation of a child orphaned in such a family is even more complex. Mallmann (2003) reports that people living with HIV and AIDS may undergo dramatic mood swings because of worry about having a deadly disease and also due to the anxiety for the future of the children after their death. Irrespective of the fact that the child may not know what is wrong with the parent or why the parent seems so moody, the child definitely notices the difference in mood and may react to this in

different ways and in some cases with fear and anxiety.

In a report on AIDS among children, EveryChild (2010) has shown that in the three countries Malawi, Ukraine and India, single parents who have lost their spouse to HIV related illness face numerous problems. The respondents of this study spoke about the stress of bringing up children alone. Several women reported finding it hard to discipline their children and a few men admitted that for them it was difficult to cook and care for the children when their spouse was no more alive. It has been highlighted by EveryChild (2010) that in India, in addition to existing gender discrimination in employment, widowed mothers who are HIV positive are generally not accepted by their late husband's or their own natal family. In many cases they are denied property rights thus making it all the more difficult for them to raise children. One can understand that the situation of children in a single parent family is no doubt a difficult one.

The Report of Child Rights for the 12th Five Year Plan enumerates that India is home to over 440 million children, the largest number in any country of the world. The total number of persons living with HIV in India has been estimated at 2.4 million in 2009. Children under 15 years account for 4.4 per cent of all infections, while 83.0 per cent of Persons Living with HIV (PLHIV) are in the age group 15-49 years. Therefore HIV and AIDS affect children irrespective of their HIV status, directly or indirectly. The loss of a parent to AIDS throws up multiple problems and the extent to which it can burden a child cannot be estimated.

Looking into the problems encountered by families afflicted by HIV, Subramanian and others (2009) have examined the psycho-social impact of HIV and the quality of life of HIV infected persons from an STI clinic in South India. The study has shown that the PLHIV, especially women, face more problems in parenting their children, experience varied stigma and have a poor quality of life, more in the social domain. According to them, fear and prejudice attached to HIV and AIDS related discrimination needs to be tackled at the individual, family, community and national levels. A more enabling environment, particularly for women, needs to be created so as to increase the visibility of people with HIV and AIDS to be treated as a "normal" part of society. Subramanian and others (2009) further emphasize that women are most often economically, culturally and socially disadvantaged and oftentimes face inequality in accessing treatment and in getting acceptance within family. A gender sensitive approach therefore is needed for them.

Hong and others (2010) have also examined the relationship between perceived social support (PSS) and psychosocial wellbeing among children affected by AIDS. A cross-sectional

survey was administered to 1,625 children (aged 6-18 years) in Henan Province of China, an area with a large number of HIV cases due to unhygienic commercial blood/plasma collection. The sample included 296 double orphans, 459 single orphans, 466 vulnerable children and 404 comparison children (children who did not experience HIV-related illness and death in family). Data indicate that vulnerable children report the lowest level of PSS compared to AIDS orphans and comparison children. Level of PSS was significantly and positively associated with psychosocial well-being even after controlling for potential confounders. The study underscores the importance of providing social support and mental health services for children affected by AIDS in China.

The available literature shows that HIV and AIDS have a profound effect on an individual, the family. The burden of illness in the family is not limited to the person suffering from the same but impacts all. Children are the future of a nation. It will therefore be apt to say that the future of a nation and the prosperity of people depend on the health and happiness of the children. Thus, the present paper examines the impact of HIV status of parent/s on education, healthcare, recreation and social interactions of the child.

Methodology:

In the context of the present study the HIV positive family comprises 'a unit of parent/s and their children living together under the same roof, where one or both the parent/s is/are HIV'. The present study is located in the National Capital Region of Delhi. It focuses on families (n = 50) where one or both the parent/s is/are HIV positive. The non-probability purposive sampling method has been used to select the respondents and the sample was accessed following a respondent led sampling plan. Both qualitative and quantitative data has been collected with pre-structured tools having both close and open-ended questions to enable the respondent to go deep into their issues. An interview schedule (semi-structured) for a one-to-one interview with parent/s has been used to obtain information.

Findings:

The HIV afflicted families in the study present a unique profile. There are as many as 22 single parent families among the 50 families included in the study. The findings show that men or women, who are heading the households, are in their middle age (30 – 40 years). This indicates the loss of spouse at an early age. The average family income comes out to be ₹6042.

Among these families, 21 are having widows and the youngest one of the widows is 27 years old. It is well understood that single parent families have to face many challenges. Not only does the parent have to earn to run the household, they also have to cope with several other challenges such as stigma

and discrimination, paucity of funds and the challenges of parenting children who have seen the death of a parent. In cases where they themselves are HIV infected, the challenges doubtless multiply_ the insecurity of the future and the inevitability of death are enough to make them suffer each moment. Issues of death and dying are stark realities they have to face head on. What then is the situation of their young ones?

Education: In April 2003, USAID in consultation with various stakeholders reached to a consensus on a set of core indicators for national level measurement of the global goals for children orphaned and made vulnerable by HIV and AIDS. Education was listed by them as a key domain needing improvement for these young ones.

The present study is having a sample of 50 adolescents growing up in HIV afflicted families. Among these 50 adolescents, 6 had to drop-out of the school. Other children continue to attend school. There are some children who are able to attend school as their elder sibling dropped out of school when the parent was diagnosed with HIV.

As many as 16 children in these families are studying in higher secondary, 22 in secondary and a small number of them (6) are in primary section. The parents of these children report that in some cases the child had to leave school for a couple of years in between to cut down the expenses or to take care of a family member and later were able to resume their education when the situation of the family improved. Due to this 6 children, who were 12 years or older had attained education only up to primary level.

Evidently, HIV disrupts the lives of children by displacing them from school and pushing them to work. Among the children included in the study, there are some who had to change their school as their family condition did not allow them to continue in the same school. As many as 31 children have changed their school. Out of these, 8 children had to change school as the family changed the place of residence after detection of HIV. Seventeen children changed their school due to financial problems which the family was now facing. These children made a shift from a private school to a government school. The remaining six children shifted to a school near to their home to cut down the travelling time and expense. Most of these children took up the responsibility of care-giving and engaged themselves in household chores after school. Evidently, their post-school time gave them little scope to study or to play.

Needless to state, continuing with schooling is a challenge for children in HIV afflicted families. In some families, parents (4) report that the child had to stop regular school and switch to distance mode of education. This was done in order to cut down on the expenses, both of schooling and travelling. In another family, a respondent revealed that he

changed his child's school three times as his resources depleted with time and it became difficult for him to pay the fee.

It is seen among the respondent families that there is at least one child in the family who had to change school for the above mentioned reasons. In fact, some children had to be sent to hostels run by different NGOs for orphans and vulnerable children. This was commonly seen in single parent families, where the living parent is a mother.

Out of 50 children, as many as 40 are attending school regularly. Among these 40 children, 9 are very irregular in attending school. These children absent themselves from school for five to ten days in a month. Eleven are somewhat regular, they absent themselves from school for less than five days in a month and the rest 20 are regular to school as they only absent themselves from school once in two or three months. Discussions with a parent bring to light a variety of reasons for irregularity of the child in attending school. The first most common reason for absenting from school is the health of the child himself/herself. Children do not keep good health to go to school. As many as 12 children, both sero-positive (3) and sero-negative (9) suffer with poor health. As many as 9 children had to frequently stay back home from school to take care of the ill- parent or to take up household chores when their parent/s were unable to do so. A debilitating ailment, such as AIDS, leaves a person with a weak immune system and a plethora of opportunistic infections.

Performance of the Child: It goes without saying that HIV affliction in a family has a destabilizing effect. Given that, many children become irregular at school while others are left with little time to study, it is important to look into the performance of the child at school. Nearly a half of the children (22) have attained sixty percent or less percentage score in their last academic session. Nearly, a third of them (16) have scored between sixty to seventy percent and only 4 of them had performed well scoring between seventy to eighty per cent. Reportedly, one child performed well attaining a score of eighty per cent in the last academic session.

It is important to highlight here that a majority of children are attending government schools and get little support from their parents due to the latter's own low education level and health concerns. However, data reveals that there are other means of support for children. As many as 24 children take private tuitions to get extra support in academics, and 14 children manage to study on their own. Two of the children, who are well connected to NGOs, take help from the organizational staff members. Parents share that help is taken by children usually before the exams, to resolve their queries and problems. Only two children in the study are fortunate enough to have support from both tutors and parents in their academics.

The importance of co-curricular activities has been emphasized by many educationists and researchers. These activities play an indispensable role in the overall development of the child. The present research has explored the participation of children in co-curricular activities organized by the school. The majority (44) of parents lament that their children do not participate in such activities and in rare cases when they do so, they do not perform well. This is mainly due to their situation at home, whereby either they are irregular or they do not get enough of parental time and support to participate in these.

Further, among the 50 respondent families only one respondent opines that the child's participation in co-curricular activities is satisfactory. Two respondents feel that the performance of children is somewhat satisfactory and three of them feel that performance and participation in co-curricular activities is low. Given this, it is very clear that an important component for development of a child is missing in the lives of many of these young ones. One can well imagine the feelings which the child may be internalizing due to his/her inability to participate for dearth of money. The situation is even more intricate for those children who have left school to take up work to meet the needs of the family. It is disturbing to see that some children never get space and an opportunity to think and to express their own interests. Do these children frolic with peers or does the family situation restrain something so natural for young ones?

Play: Play comes to a child as a natural act with a lot of value. Aggarwal and Gupta (2007) discuss that many educators like Froebel, Montessori and Pestalozzi have recognized the role of play activities in the all round growth and holistic development of the child. According to them, psychologists like Piaget and Gesell have also emphasized upon the role of play in the development process of the child. Play has been considered as an effective learning situation for the children. It helps to develop gross and fine motor skills. It gives opportunities to learn cooperation, helping, sharing, taking responsibilities, and making choices. It encourages self expression and enhances creativity. It helps children to get control of their own behaviour, to learn to care for themselves and much more (Aggarwal and Gupta, 2007).

This research looks into involvement of children in play activities. A close look at the data obtained from respondents shows that 28 children out of 50 do not spend time with their friends. Fourteen children spend very little time with their friends for play. Only 7 children get a lot of time to spend with friends. The remaining one child, a fourteen year old, never gets time to spend with friends as he is involved in work that is being carried out at home_ producing wooden brushes along with the family to earn money.

It is clear from the above findings that most of the children keep to their homes and do not spend much time with their friends outside home. It becomes necessary to have a look into the leisure activities taken up by the children at home. Data shows that a majority of children (36) spend their leisure time watching television. Two of them play indoor games and two prefer to read books. Some others (4) spend their leisure time drawing, painting and dancing. A small number (4) do nothing in their leisure time whereas some (2) do not find time for any leisure activity in their routine.

Child and Family Situation: There is extensive literature on the changes seen in children surrounded by chronically ill parents or relatives. Visser and others (2004) have reviewed the impact of parental cancer on children and the family. The authors emphasise that both qualitative and quantitative studies have reported anxiety and depression in adolescents and qualitative studies have found behavioural problems in school-aged children and changes in cognitive and physical functioning in children of all ages. Research has also looked upon the children growing up in HIV afflicted families and studied their behavioural responses after they come to know the positive status of the parent/s (Shaffer and others, 2001; Lee and others, 2002). This paper also explores the changes observed by the parents in children and these are discussed in the following section.

According to parents, as many as 24 children, show changes in their behaviour. The remaining 26 do not show any change. Those who have shown changes in their behaviour (24) have turned more caring and concerned towards their parent/s. These children have also stood up to shoulder the responsibilities and have taken up household chores. Parents inform that some children restrain themselves from moving out and have stopped going out or indulging themselves in outdoor activities. One of the respondents, talking about her daughter, shared that her daughter has started keeping quiet, she has stopped sharing and expressing herself like her siblings. She provides support to her mother in every possible way but does not share her feelings with anyone. The respondent feels that her daughter keeps things to herself to avoid giving unnecessary stress to her mother.

Another parent, a father, shared about his daughter and discussed that she appears to be occupied with her own thoughts. She has become slow in her work and needs motivation again and again to keep working. She does not take any initiative to do any work herself. One of the respondents (a mother) also shared an unexpected behaviour from her son. She stated that her son suddenly withdrew himself from responsibilities of home and did not bother to provide care to his mother at the time of illness. This change came about after HIV status disclosure

which the mother did as she was looking for support and understanding from her only son. The respondent had earlier lost her husband and daughter to HIV years ago. Her son is the only family member around as she had been abandoned by her in-laws after the death of her husband.

Another mother shared that her son had turned aggressive, irritating and demanding but at the same time he cries and gets upset when he sees his mother or father being unwell. Yet another parent shared that his child gets disheartened and sad seeing parents struggling with illness. The child does not eat well when he sees his parents suffering from illness and not being able to live a normal life.

There are many NGOs who are working to address the needs of this young group of children growing up in the HIV afflicted families. It is important to investigate how parents use these services to tackle the behavioural issues of their children following the diagnosis of HIV. Out of the twenty four respondent families who have experienced a change in the child's behaviour, as many as 14 are not aware about availability of such services and do not know whom to approach for help. The remaining 10 families have taken initiative to link their children to counsellors and outreach workers of NGOs for help with regard to the behaviour of the child. The respondents who are linked with some organization for their children mention that they continue to face diverse issues with regard to their children. Only one parent mentioned the positive impact of organizational services. He elaborated that his son, with the help of professional intervention understands the needs of his parents and takes utmost care to provide support in managing household responsibilities. This indicates that there is a need to develop interventions for the parent/s and the child to cope with difficult situations, and understand their changed family situation better.

The experiences of the respondents regarding behavioural changes seen among children and the nature of their access to available services, confirms that the condition is somewhat demoralizing. Attention needs to be paid to the availability and accessibility of services for these families so that they have professional support to address the issues related to children.

Psychological Support and Relationships: Family environment, parental support and communication channels and interaction among the family members can predict support systems and emotional satisfaction. In the context of the present study, it is important to look at the support available to the child within the family. As reported by parents, as many as 28 children spend maximum time with their mothers. Nine children spend most of their time with siblings as the elders in the family are generally away at work for long hours. Some children (4) prefer spending maximum time with their father and another four with other adults

living with the family such as grandparents, uncles and aunts. The remaining 3 children spend their time with their friends and relatives living in the neighbourhood. Two children do not spend their time with any specific person. In fact all their time is spent in working to add to family income.

Given the demands of the contemporary society, parent-child interaction is hardly to be seen. However, in case of HIV afflicted families the lack of such interactions assumes a pointed significance. In 22 families out of the 50 families there is only a single parent and as many as 19 of these single parents are HIV positive. Quite understandably, parent-child relationships have taken a new shape in these families.

A close look at the information provided by the respondents highlight that a large majority of children (32) share their emotional concerns with their mothers. Three children share their close thoughts and emotions with their fathers. There are 4 children who like to talk to both the parents about their concerns and emotions. It is also interesting to note that as many as 4 children confide their concerns with other adults living along like a grandparent, uncle or aunt instead of their parents. Two children confide with their siblings and another two children with their friends. Further, it is distressing to note that as many as three children do not share their concerns with anyone.

It is not only important to understand the adjustment problems faced by the children but also the change in the relationships within the family. Information provided by the respondents goes to show that as many as 16 children are facing a change in the relationships with extended family members due their parents' HIV status. The relationships became strained after the revelation of the HIV status in one-third of these families. Probing deeper into these relationships, parents shared that their children are mostly clueless about the reasons why their grandparents, uncles or aunts are no more affectionate towards them. However, there is a change in the affection shown and this for them is a harsh reality.

Family Time-out: Recreation is an important part of family living. It helps strengthening family bonds and has a positive effect on physical, mental and social life of all the family members. Recreation helps avoid stress, boredom and depression. It is also known to develop self esteem and confidence. It has been recognized that rest, relaxation and revitalization through recreational activities with family members is a big stress reliever in the busy lives of people.

The data shows that a majority of the respondents (40) report that their family members rarely go out together. Only 5 report that their families get an opportunity to go out and that too once in three months. A few families (3) get time to go out once in a month and the remaining two families go out

once in two weeks. The recreational activities include going out to a market, a park or going to a religious place. The reasons which have come out for rarely going out are primarily lack of time, occupation with work, financial constraints and health concerns. Respondents have also informed that for most of the families, visit to their native place is the only family outing which is mostly on an annual basis. Furthermore, it has been reported that these families get very less time to spend together.

Child's Understanding of Health, Illness and Family Situation: One of the key concerns of every HIV positive parent is disclosure of his/her HIV status to the child. There is always a dilemma and there is a fear of rejection, disrespect and abandonment. Findings shows that out of 50 families as many as 18 parents have given all information about HIV and their positive status to their children. An observation which comes out of the data is that these 18 children who are aware about their parent's HIV status are above the age of 15 years. Further, in as many as 23 families, children are familiar only with the name of the illness their parents are suffering from. Children know that their parent/s suffer from an illness called AIDS that requires maintenance of good health, good food and timely medication with regular health checkups. The children also remind their parents to take their medicines on time. Parents have not shared with them details such as modes of HIV transmission or have partially shared one or two modes of transmission. Reportedly, some of these children also accompany their parent/s to ART centers for medical checkups, medicines and follow-ups. It is also essential to mention here that out of these 23 children some of them are sero-positive themselves. It is only in nine families that parents have not disclosed their positive status. Some of the reasons which have been given by the parents for not sharing their positive status with children include age of the child, waiting for the right time and occasion, and unpredictability of the child's response after disclosure. It needs a special mention here that in one family, the father is surrounded by a strong fear of rejection which has stopped him to share his illness with his children. He has given false information to his children. Some parents feel that children should get to know things according to their age and thus have been sharing things with children slowly. Some parents have taken help from NGOs in the process of disclosure. In two of the families children have got to know about their parent's HIV positive status by seeing medical reports of their parents. Both the children in these families are girls and had previously heard about HIV to be an incurable illness in school.

Conclusion:

In the light of the above findings, it can be said that children growing up in families affected by HIV

have different issues and challenges. Each aspect of their development be it education, play, recreation and social interactions during the formative years of their lives is affected. As previously discussed, many children in the present study research have compromised schooling. Some have dropped out to earn money for their family. Children take care of their ailing parents. They shoulder the extra responsibility of domestic chores and become mature early of their age, taking the role of an adult in the family.

The HIV stricken families offer an environment for the development of young children where parents are uncertain of how long they will live and be able to ensure a secure environment for their children. They find themselves in difficult circumstances where their children are required to compromise on basic needs of education, extra-curricular learning, play time and even nutrition. Can one expect that children coming out from such environment will grow into normal and healthy adults? The implications of such challenges that HIV throws on a family are many and need to be especially understood by policy makers, programme planners and implementers at each level. Some recommendations that emerge out of this research are:

- (i) Addressing behaviour and adjustment problems in time is essential to ensure normal development of children and thereby their smooth transition into adulthood. In this regard, both parents and children of HIV afflicted families need to be involved in such programme activities where parents are enabled to identify behaviour and adjustment problems among their children, develop skills to handle these concerns and seek expert guidance if required. An intervention plan designed to make both the parents and children participants in the process of understanding and coping with their problems is required. Professional intervention, mainly by those who come in contact with these families such as outreach workers and counsellors has an immense role to play. One needs to reiterate that although AIDS continues to be terminal in nature, in no way, it means death soon after diagnosis. Both parents and children can be helped to live these years together happily and fruitfully.
- (ii) Life Skill Education Programmes have proven effectiveness in meeting the needs of adolescents. These can be increased and up-scaled for children belonging to HIV afflicted families. This will provide them with peer support, help them strengthen relationships within family and learn to build trust. Above all, with experienced adults supervising these activities, these children can be helped to develop their confidence level, self-awareness, self-image and self-esteem. These

would definitely contribute towards strengthening their coping skills in daily living and also in future.

- (iii) In some families, it is seen that children have dropped out of school, and taken up work for supplementing the family income. There are other children who speculate on what they would do after their schooling ends. Given that future insecurities are high for children of HIV afflicted families, proper guidance, mentoring and career counselling assume a pointed significance. Having been provided with a direction, they will be able to utilize the existing resources, enhance their earning capacities and be able to position themselves

better in order to take up the challenges that the future holds for them.

- (iv) Lastly, it is seen that sharing of HIV positive status by a parent creates turmoil in the family. In some cases children immediately accept, others do so gradually, yet a few are never be able to do so. Outreach workers, counsellors and other service providers can do a lot of strategic hand holding and be supportive to a family to tide over these difficult times. To conclude, it is important that these families have professional support and guidance as the very foundation of happy co-existence has been eroded with the HIV entering into their lives.

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