International Research Journal of Human Resources and Social Sciences
ISSN(O): (2349-4085) ISSN(P): (2394-4218)
Impact Factor- 5.414, Volume 5, Issue 02, February 2018
Website- www.aarf.asia, **Email** : editor@aarf.asia , editoraarf@gmail.com

BEHAVIOURAL ISSUES IN CHILDREN LIVING WITH HIV/AIDS

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ABSTRACT

The children with HIV/AIDS are at increased risk of facing violence against them. A few studies have examined the co- occurrence of violence against children with HIV/AIDS, deprivations caused by progressive HIV infection and development of behavioural issues in them. The objectives of the study were to investigate the impact of violence against children with HIV/AIDS, deprivations caused by progressive HIV infection in families and emergence of behavioural issues in them. Thirty children who were in the age group of 07-14 years and their mothers were selected from the nongovernmental organizations working for families living with HIV/AIDS. We used face to face interviews with children and their primary care givers, observations, standardized test on Self Perception Profile developed by Susan and Harter and narratives of children to generate data. All children reported violence against them either due to their own or their parent(s) HIV status. Deprivations associated with progressive HIV infection aggravated the behavioural issues in children living with HIV/AIDS. Aggression (27) was the most frequently reported behavioural issue in children followed by stubbornness (24), mood swings (21), disobedience (21), use of abusive language (18), sleep disturbances (9), nightmares

(7), bed wetting (5), fear of ghosts (3), truancy (3) etc. Most children had more than one behavioural issue.Our data raise concern regarding the impact of societal attitudes towards the children living with HIV/AIDS and deprivations caused by progressive HIV infection which put them at a risk of developing behavioural issues. Provisions of free regular mental health checkups and optimal care and support services for children living with HIV/AIDS are essential for their all-round development besides awareness generation strategies about HIV/AIDS for general public at a war scale.

Key words: Children with HIV/AIDS, crises, violence, deprivations, behavioural issues.

Introduction: HIV/AIDS is not just a health problem but a social problem too. The impact of it on families and children is complex and multidimensional. The children are the tragic by-product of HIV/AIDS epidemic in most cases. Millions of children have been orphaned or made vulnerable by the infection. HIV/AIDS aggravates the effects of poverty on young children and cuts their childhood short. The vulnerability of children living with HIV/ AIDS starts well before the death of the parent (s). The emotional turmoil of the children begins with the parents' distress and progressive illness. It gets compounded with the drastic changes in the family, heavy disease related expenditure on health, forcing children to become caretakers and breadwinners and experience stigma, discrimination, blame and rejection. Eventually, the children suffer the death of their parents and the emotional trauma involved. They then have to adjust to new situations with little or no support and may suffer exploitation and abuse.

HIV/AIDS in India

The initial cases of HIV/AIDS in India were identified in 1986. These were from commercial sex workers (CSW) of Mumbai and Chennai and injecting drug users (IDU) of Manipur in 1986 (National AIDS Control and Prevention Policy, 2002). An estimated 2.27 million people were living with HIV in 2008 as per the annual report 2009-10 of National AIDS Control Organisation (NACO). India is the third worst affected country after South Africa and Nigeria. The epidemic in India is showing a declining trend as HIV prevalence rate among adult population. Thirty nine percent of total HIV infections are among women while children under 15 years of age account for 3.5 percent while 83% of the infections are in the age group of 15-49 years (NACO, Annual Report, 2010-2011). In the initial phase of the HIV epidemic, HIV infection in children was

observed mostly as a consequence of blood transfusions. Subsequently, the parent to child transmission of HIV became common as the hetro-sexual mode of HIV transmission was identified and women became increasingly affected by HIV epidemic. 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.

Prevention of Parent to Child Transmission programme (PPTCTP) was initiated in 2001 in India as it was recognised as the major cause of HIV transmission in children below 15 years of age. Pregnant women are provided with counselling and testing service through this programmePaediatric ART is provided at all ART centres. Around 10,000 children were put on ART in the first phase of 'National Paediatric HIV/AIDS initiative'. Presently 79,719 children are registered for ART. Approximately 22, 837 children were alive and were receiving free ART in 2010-2011 (NACO, Annual Report, 2010-2011).

The review of literature on HIV/AIDS and children showed that the approaches to meet the needs of children living with HIV/AIDS have mostly focussed on material support and meeting children's physical needs. Behavioural problems have been consistently documented in the literature for children living with HIV/AIDS. It is unclear, however, whether HIV is the causative agent or a compounding factor. There is a need to focus on psychosocial needs of children having HIV infection, children caring for sick parent(s), children who are at the verge of losing one or both parents. The loss of a parent is a traumatic and stressful experience for children of any age.

The HIV/AIDS epidemic endangers children's basic human rights, including their right to survival, health, development, education, rest and leisure, and protection from abuse and neglect, sexual and economic exploitation. Orphans are more susceptible to HIV infection as these children lack parental guidance and support and are emotionally distressed. They may get involved in risky sexual relationships in order to meet their emotional needs. Those children who live on their own or on the streets are often sexually active at younger age than other children, and are also more exposed to rape and sexual abuse. They often lack information about sexually transmitted infections, including HIV/AIDS and how to protect themselves. They also lack access to protective health services.

Families in which one or more members have HIV/AIDS undergo extraordinary stress. Parents with HIV reported feelings of extreme isolation, stress and anxiety concerning their own and their child's health and financial burden of illness **(**Mallins & Ehrhardt, 1994**).**

The findings of Ishikawa, Pridmore, Carr-Hill & Chaimuangdee, 2010 strongly suggested that adults created a "wall of silence" around children affected by AIDS. They did not reveal their HIV status to them and avoided talks about HIV and AIDS. It was found that though the silence was intended to protect the children from sadness, embarrassment, bullying, and discrimination but, it actually isolated children and increased their psychosocial vulnerability by blocking open communication with family members, peers, and teachers, and left them to cope with their problems on their own.

A study conducted in 1993 at Malawi on orphans, revealed that many of them, especially the double orphans, were stressed and traumatized, and was at risk of committing suicide (International HIV/AIDS Alliance, 2005). Another study conducted by Senegendo & Nambi, 1997 examined psychological effects of orphan-hood on 193 children in Rakai district of Uganda. The study found that the children living with widowed fathers and those living on their own were significantly more depressed.

A cross-sectional survey conducted in western region of Sub Saharan Africa (Ghana), four groups of 200 children (children whose parents died of AIDS, children whose parents died of causes other than AIDS, children living with parents infected with HIV/AIDS, and non orphaned children whose parents are not known to be infected with HIV/AIDS) aged between 10 and 19 were interviewed. The researchers concluded that orphans and children living with parents infected with HIV/AIDS are at heightened risk for emotional and behavioural disorders and that efforts to address problems in children affected by HIV/AIDS must focus on both groups of children (Doku, 2009).

The children with HIV/ AIDS face discrimination in all walks of life-schools, medical facilities, orphanages, their neighbourhoods, and in their own homes. Doctors, both government and private, sometimes refuse to treat and often do not touch HIV-positive children. Incidences have been reported in the national dailies off and on where schools have expelled or segregated children because they or their parents are HIV-positive.

From the above studies, it can be concluded that orphan-hood causes psycho-social and behavioural issues in children. An attempt has been made through the present study to explore the causes of violence against the children living with HIV/AIDS, deprivations caused by progressive illness and emergence of behavioural problems in them.

Objectives:

1. To examine the profile of children living with HIV/AIDS in families
2. To gain insights into children's understanding of the illness and its impact on their lives
3. To investigate the emergence of behavioural issues in children living with HIV/AIDS

Methodology

The review of literature revealed the paucity of research studies undertaken on children affected and infected with HIV/AIDS in India, the present study is an exploratory research in this area. It focuses on a situational analysis of children living with HIV/AIDS and employs mixed methodologies approach ie both a qualitative and a quantitative approach. The sample comprised of 30 children living with HIV/AIDS in familial set up who were in the age range of 7-14 years. To understand children's lives in their contexts, caregivers medical personnel and counselors were also made part of the sample. Thirty mothers of familial children, caregivers, doctors and community level workers were also the part of the study.

Purposive sampling method was adopted to identify the respondents among the children. The children who could articulate figured in the sample.

Tools for the study

The following tools were prepared for the study:

- Interview guides- Children, Care givers and institutional heads
- Observations-Care givers, Children, Community level workers (while working with families living with HIV/AIDS & other families in the community) and doctors
- Group discussions-Parents and children
- Narratives of parents and children

Ethical Concerns: Written consent was taken from the parent/s to interact with the children. Oral and written consents from the familial were also taken. The families and children were assured of the confidentiality.

Results and discussion: HIV/AIDS redefined the meaning of childhood for the children who were living with it. It made many children poorer and malnourished, homeless, sick but devoid of health care, school drop outs etc. Older children became bread earners to support their family when no adult was well enough, and became parents to their younger siblings – children raising children.

Demographic profile*:* All the children were vertically infected with HIV/AIDS. Eighteen familial children lost their fathers to HIV/AIDS. All children except one child under study were going to school. Their HIV status was not disclosed in the schools. Out of seven HIV positive children, six were on ART. Education level of the parents varied from illiteracy to graduation. Most parents were either illiterate or had education up to primary level. Most families belonged to very lower income group.

Marital discord associated with domestic violence, alcoholism, indulgence of male spouses in high risk behaviors were lethal combinations and defining features of family life in the children studied. HIV infections were often hidden from the spouse and only came to the fore after some acute episode of infection. The resultant social isolation from relatives left the family quite alone in coping with the trauma of the illness. The Indian family characterized by collectivism and "familism (Anandalaksmy, 1984) showed 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. There was delayed HIV testing of wives and children and non adherence to Anti Retro -viral Therapy (ART) in the families.

Impact of HIV/AIDS on family functioning: The most major impact of HIV on children's lives was the death of the father. HIV/AIDS and the death of the father led to many crises in the families and in the lives of the children. There were frequent outbreaks of opportunistic infections among male spouses which led to absenteeism and consequent loss of wages. Other impacts were financial crisis, mother headed single parent families, absence of adults in the family and deterioration in the quality of food taken at home. The families experienced stigma

and discrimination from extended family members. The stability of the children's life was affected.

Substantial and every day practical challenges 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. This led to irregular daily wages. All the children used to share household responsibilities.

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. There were breaks in the study. Some children were shifted from private schools to government school because of severe economic crisis caused by parental illness. The children faced stigma and discrimination from the relatives. All the children used to share household responsibilities. The performance of household tasks by the children was dependent on HIV status, age, number of members in the family and employment status of the mother. More tasks were performed by affected, older children of working single parent HIV positive mother headed households.

All children reported experiences of having seen severe parental fights at home. Most of them also reported the incidences of extreme domestic violence like wife beating, hitting, cutting wife's hand with knife, head banging etc on the part of the father in drunken state. Parent(s) in the fit of anger also used to hit their children a lot. Absence of adults in home for most part of the day and neglect of children were some of the major effects of parental illness and subsequent death.

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.

A few children were admitted into residential institutions after the death of one or both parents. There was segregation of siblings. The placement of children in residential institutions was the step imposed on them either by the circumstances or by their living parent(s)/ siblings/ relatives/ NGO personnel/ doctors.

Disclosure of HIV status: There was no formal disclosure of HIV status to familial children. The older children (11-14 years) knew the HIV positive status of the family. The younger children (7-10 yrs) had the feeling that they or their parents were sick with some serious illness. The paternal and maternal family members knew the HIV status of the families. It was not disclosed in the neighborhood and the school. It seemed that the CLHIV 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.

Behavioral issues in children: All families reported one or more behavioral issues in their children which were the cause of parental worries. The CLHIV faced wide range of emotionally traumatic events like losses, crises, difficulties and isolation which might have triggered the development of behavioral issues in children. One of the mothers reported, '*My son often says that he will runaway one day'*. Twenty seven families found their children very aggressive. One of the single mother reported that her son threw things in anger. If his wishes were not fulfilled, he would get angry. Stubbornness in children was reported by twenty four mothers. Twenty one mothers reported mood swings in their children. Twenty one children did not follow parental commands. Eighteen children used abusive language. Nine children had the problem of sleep disturbances and seven children used to have nightmares during sleep. Five children had problem of bed wetting till the age of 08-09 years. Three children had fear of ghosts. Three mothers reported truancy in their male children. Two children had the problem of bruxism during sleep. Two infected children had problem in waking up. Two children had taken treatment for epileptic attacks. Two children had speech disorders. They were not interested in studies. Another mother reported that her children fought a lot on allocation and performance of household tasks. Parents of infected children reported that they had low appetite and weak memory. One of the HIV negative children ate cement from the walls. She had made pits in the walls. One child complained of headache.

Children's worries were related to parental or their health, finances, school and exams. The children also reported their worries for not gaining height, sudden reduction in weight, feeling giddy at times, headache etc. Out of eleven children, three used to bed wet and two were having encopresis.

Familial children watched TV, played with friends or tried to sleep to avoid worrying. The institutional children prayed to God to keep their family members healthy and alive.

Parental worries about children: The worries were related to care choices, wellbeing and the future of their HIV positive children after their death as well as everyday parental anxieties.

Succession plan: Most parent(s) wished to bring up their children on their own. But they reported that the fulfillment of their wish was dependent on their sound health and financial status. Most families had no concrete succession plan for their children in place.

Conclusions: The HIV/AIDS infection caused suffering and deaths in the families and pain and angst in lives of children. It had an adverse impact on various aspects of the stability of child's life. Families and children were learning to live with the disease. 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 CLHIV faced wide range of emotionally traumatic events like losses, crises, difficulties and isolation which might have triggered the development of behavioral issues in children. The children living with HIV/AIDS had restricted care choices. The psychosocial distress and well-being co-existed CLHIV.

Recommendations

1. These is a need to recognize that AIDS affected families do not comprise a homogeneous category. It is essential to recognize differences in family types.
2. There is a strong need to create awareness about various governmental schemes for poor people, women and children.
3. Exploration, identification and strengthening of the intra and inter-personal resources of women will immensely help them in coping with HIV/AIDS.
4. Psychosocial support should be provided for children living with HIV/AIDS. Grief counseling should be incorporated in the programmes.
5. All decisions on alternative care, whether formal or informal, must be guided by the best interests of the child, taking into account the concerns and wishes of family members and children.

6. There is a need to take into consideration the reproductive and sexual health needs of the children living with HIV/AIDS. '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.
7. There is a need to update the knowledge of HIV affected families about HIV/AIDS. There should be greater involvement of PLHIV and CLHIV in the programme and policy design, planning, implementation, monitoring and evaluation.

Though the present study is a micro level study centering on families living with HIV/AIDS in Delhi and residential institutions situated in and around Delhi and only thirty children living with HIV/AIDS from four institutions and 30 families living with HIV/AIDS were sampled for the study but it has explored many important facts about CLHIV. The PLHIV and CLHIV who participated in the research were residing in Delhi where awareness level and access to services was better in comparison to PLHIV and CLHIV residing in hard to approach areas. Research on PLHIV from such areas will immensely help in developing the realistic picture of the impact of HIV/AIDS.

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