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PSYCHO SOCIAL AND ECONOMIC IMPACT OF THE HIV INFECTION IN THE CHILDREN ON THEIR FAMILIES

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ABSTRACT

Back ground

HIV infection in children leads to various psychosocial distress in the family members. It also impacts negatively on the economy of the family. These parents or care giver devise their own coping mechanisms to overcome these challenges. This study aims to describe the psychosocial and economic impact of HIV infection in the children on their families. ***Material and methods****: This cross sectional semi qualitative study was conducted at PCOE, Indira Gandhi Institute of Child Health, Bangaluru, between January 2014 to June 2014. A pre tested questionnaire was designed containing 23 questions covering demographic data, psychosocial issues and economic impact of the HIV infections. The parents or caregivers of the HIV infected children were interviewed after taking informed consent.* ***Results:*** *We included 50 families with HIV infected children in this study. Majority of the parents (56% of the mothers and 44% of the fathers) has not attended the school and most of the primary care givers for these HIV infected children were either both parents or only mother (38%). Majority of these children were paternal orphans (44%) and in half of these families the burden of HIV was more than 3. This infection has led to broken family in 56% of these study subjects. Among the 91% of the families who have disclosed their HIV status to the other family members, 42% were accepted by the extended family members and 40% of them faced discrimination in various forms including physical abuse (26%) and not sharing the food (16%). The predominant coping mechanism was ignoring acts of discrimination (40%). When the HIV was diagnosed one third of them had suicidal thoughts and 58% of them were worried about their child's future. There was significant decline in the family's income following the diagnosis of HIV infection. There is also significant increase in the expenditure on the medicine and decrease in the expenditure on food, entertainment and travelling.* ***Conclusion:****HIV infection in the children leads to adverse psychosocial and economic consequences to the families. These psychosocial stresses further deteriorate the fragile economic situation of these families.*

KEY WORDS

Psychosocial impact, HIV infected children, economic impact, families with HIV

INTRODUCTION

India has a low prevalence of HIV (0.27%) epidemic with an estimated 21 lakh People Living with HIV (PLHIV). Due to scale up of free Anti-Retroviral Treatment (ART) since 2004 combined with consistent activities to increase the awareness and targeted intervention among high risk group, the adult HIV prevalence has decreased from 0.41% in 2001 through 0.35% in 2006 to 0.27% in 2011. There has been 29% reduction in estimated annual AIDS-related deaths from 2.07 lakhs in 2007 to 1.48 lakhs in

2011 highlighting the impact of scale up of free ART services in the country. As per 2011 estimates, nearly 7% of those infected with HIV are children and nearly 1, 45, 000 children are estimated to be living with HIV with 14,522 new infections every year among children [1].

However, this decrease in the mortality and increased survival has led to paradigm shift from medical to complex psychosocial and economic challenges faced by these PLHIV. There is a tremendous economic stress on these families with HIV infection due to loss of income resulted from sickness, discrimination at workplace, death of earning members of the family as well as increased expenditure on medicine, nutrition and travel.

Traditionally, India being a family centered society, family plays an important role in the care of HIV infected children. HIV infection results in altered family dynamics and strains the relationship within the family. Also HIV infected individuals and families have to cope with multiple stressors due to prevalent stigma and discrimination in the society. These challenges can interfere in overall functioning of these families especially in the care of the child affected or infected by HIV. Many of the available literature from India are from the preART period and focus of these studies was on psychosocial problems of adults rather than children. As we are moving into the second decade of free ART services, there is diversification and emergence of new challenges. Hence we aim to study the psychosocial and economic impact of HIV infection in children on their families in the context of improved survival and Quality of Life (QOL).

MATERIAL AND METHODS

This study was conducted at PCOE, Indira Gandhi Institute of Child health, Bangaluru between January 2014 and June 2014. This is a cross sectional qualitative and quantitative study done using a pre structured questionnaire to assess the psychosocial and economic impact of HIV infection in children on their families. We included families with HIV infected children less than 18 years. We excluded HIV infected children who are in the institutional care.

Questionnaire was designed based on a review of studies of psychosocial impact on caregivers [2]. Questionnaire contained 23 questions which covered:

(1) Demographic information about the child and caregivers; (2) Psychological and social issues and (3) economic impact as assessed by calculating the difference in the economic situation including percapita income and source of income, diversification of spending of the family before and after the diagnosis of HIV. This questionnaire was pretested in a pilot study involving 5 families, by two independent interviewer to test the reproducibility of the meaning those questions are intended to. These 5 families were not included in the final analysis. The questionnaire was also translated into local languages before pretesting.

Confidential face to face interviews in the language of preference was conducted with parents of eligible HIV positive children and in some cases with the care givers, after obtaining informed consent. To elicit unbiased response from the parents or caregivers interviews were conducted by trained research assistance who was not part of the clinical team involved in the care of these children.

Questions were administered first to know the social and economical issues faced by the family due to HIV infection and later psychological issues. Written and informed consent was taken from parents or caretakers of subjects included in the study.

Ethical committee approval

The study was approved by the Ethics Committee of Indira Gandhi Institute of Child health, Bangaluru

Statistical method used

All data were recorded on a paper during the interview. Later, data was entered into a computer using Microsoft Excel software. Descriptive statistics were used on all psychosocial variables to test frequency of distribution. However, to test for difference between economic status before and after illness, Parametric inferential statistics (student't') were used.

RESULTS

In our study, majority of the children were between 6 – 10 years of age with median age of 8 years (mean age is 8.3±3.4years). Male to female ratio of the study subject was 0.85:1(Table 1).

Table 1: Demographic features

Age in years	Male	Female	Total
0-1 years	4	6	10 (20%)
6-10years	14	15	29 (58%)
10-18years	5	6	11 (22%)
Total	23	27	50

Table 2: Factors affecting the psychosocial and economic issues

Parental education		
Level of education	**Father**	**Mother**
Not attended school	22 (44%)	28 (56%)
Primary school	13 (26%)	8 (16%)
Secondary school	10 (20%)	12 (24%)
College and above	5 (10%)	2 (4%)
Relationship of primary care giver with the child		
Relationship	**Number**	**Percentage**
Father only	3	6%
Mother only	19	38%
Both parents	19	38%
Grand parents	3	6%
Uncle and aunt	6	12%
Index case in the family		
Father	25	50%
Mother	12	24%
Child	13	26%
Stage of HIV during the interview		
At the time of diagnosis	6	12%
During ART follow up	30	60%
During intercurrent Illness	14	28%
Caregivers interviewed		
Father	12	24%

Mother	29	58%
Grand parents	3	6%
Uncle and aunts	6	12%

Table 3: Social impact of HIV infection

Mortality status of parents	Number(n=50)	%
Both parents alive	19	38.0
Only mothers died	5	10.0
Only father died	22	44.0
Double orphan	**5**	**10.0**
Burden of HIV in the family		
≥4	**15**	**30%**
3	**27**	**52%**
2	**5**	**10%**
1	**3**	**6%**
Type of family		
Nuclear family	21	42%
Broken family	28	56%
Joint family	1	2%
Social support		
Disclosed to other family member (n=45)	**41**	**91**
Reaction to disclosure to other family members		
Acceptance	21	42
Isolated	10	20
Discriminated	20	40
Discrimination faced		
Never	30	60%
Rarely	3	6%
Sometimes	10	20%
Often	7	14%
Type of discrimination		
Thrown out of house	7	14%
Physical abuse	13	26%
Not sharing food	8	16%
Hesitant to touch	5	10%
Denied school admission	3	6%
Discrimination at work place	7	14%
Coping with discrimination		
Change of school	6	12%
Change of work place	7	14%
Self isolation	10	20%

Ignore	20	40%
Feeling helplessness	13	26%
Complaining to authorities	3	6%

Table 4: Psychological impact of HIV infection

Response when their HIV infection was diagnosed	Number (n=41)	%
Suicidal thoughts	13	31.7
Depressed	8	19.5
Feeling cheated by partner	3	7.3
Anger towards spouse	4	9.8
Acceptance	6	14.6
Helpless	7	17
Worry of future	4	9.8
Shock	9	21.9
Denial	6	14.6
When the HIV infection of the child was diagnosed		
Depressed	5	12.2
Guilty	23	56.1
Worry about future of the child	24	58.1
Angry and blame towards child's father	3	7.3
Concern about her/his own health impacting the child care	13	31.7
Fear of death	10	24.4

Table 5: Economic impact of HIV infection

Economic variables (n=44)	Before diagnosis	After diagnosis	P value
Income/month (Rs)	5062.0±2340.8	3872.00±1934.0	<0.001**
Earning member	1.58±0.88 (median=1.00)	2.88±1.53 (median=3.00)	
Expenditure on medicine (Rs)	2.90±3.21	26.00±7.89	<0.001**
Expenditure on food (Rs)	53.10±6.05	49.50±7.97	<0.001**
Expenditure on Entertainment (Rs)	103.20±33.16	40.40±12.22	<0.001**
Travelling expenses	36.10±6.87	24.60±10.29	<0.001**

In our study, 44% of the father and 56% of the mother has not attended school. Both the parents were primary care giver to the 38% children and in another 38% of these children it was only the mother. But extended family members were the primary caregivers to 18% of CLHIV. Father was the index case in 50% of the families diagnosed with HIV infection. When the interview was conducted 60% of these children had come for routine ART refill follow up and 28% for intercurrent illness. Majority of the people interviewed were mother (58%) followed by father (24%) (Table 2)

Social impact

Majority of the children were paternal orphans (44%) and 10% were double orphans. However, 38% of the children had both living parents. In 50% of the families the burden of HIV, as measured by the number of people living with HIV infection in the family was 2 and in 16% of the families it was more than 4. Fifty six percent of the children were living in broken family. Ninety one percent of these families had disclosed their HIV infection status to the other family members. When their status was disclosed to the other family members, 42% accepted it and 40% of them faced discrimination. Nearly 34% of these families faced frequent acts of discriminations (14% often and 20% sometimes). These acts of discrimination was in the form of physical abuse (26%), not sharing the food (16%), thrown out of the house (14%) and discrimination at the work place (14%). These family's coping mechanisms include ignoring (40%), feeling helplessness (26%) and self isolation (20%) (Table 3)

Psychological impact

When the HIV infection of the parents was diagnosed, 31.7% of them had suicidal thoughts, 21.9% of them were in shock and 19.5% were depressed. Whereas 58.5% of them started worrying about their child's future and 56.1% of them felt guilty when the HIV infection was diagnosed in their children.(Table 4)

Economic impact

Economic impact was assessed in 44 families as 6 families were newly diagnosed with HIV infection. The per capita income of these fell from Rs. 5062.0±2340.8 before the diagnosis of HIV infection to Rs. 3872.00±1934.0 after the diagnosis. This was statistically significant (p=<0.001). There was increase in the earning members from 1.58±0.88 (median=1.00) to 2.88±1.53 (median=3.00) before and after diagnosis. There was significant increase in the expenditure on medicine (from Rs. 2.90±3.21 to Rs. 26.00±7.89) before and after diagnosis (p= <0.001). However there was significant decrease in the expenditure on food (from Rs. 53.10±6.05 to Rs. 49.50±7.97), on entertainment (from Rs. 103.20±33.16 to Rs.40.40±12.22) and travel expenses (from Rs. 36.10±6.87 to Rs. 24.60±10.29) before and after diagnosis (p=<0.001). (Table 5)

DISCUSSION

As Indian society is a strongly family centered with many of them living in joint families especially in rural India, these families face serious social challenges due to HIV infection resulting in many psychological problems. Most of the HIV infection in India occurs in people belonging to marginalized population with limited economic opportunities and hence puts a lot of economic strains on the families. This study used both qualitative as well as quantitative methods to examine the psychosocial and economic impact of HIV infection in children on their families.

The relationship of the primary giver with HIV infected child determines the psychological issues these families face. In our study, only 38% of them had both parents as primary care giver and in rest of the families it was either of the parents alone or members of the extended family like grandparents or uncle or aunts. This is similar to the study from costal Karnataka, where they found that 37% of their primary care giver was both parents [3].

In 50% of the families, father was the first individual to be diagnosed with HIV infection. When the interview was conducted, majority (60%) of these families had a stable disease who had visited for ART refill follow up.

Social impact

Majority of these children (62%) were orphans either single or double due to death of parents

with HIV infection. As the father is the primary earning member in the majority of the families, if not all, paternal death leads to severe economic hardship to the child and family. Similarly, mother is an important emotional source to the child as well as the primary individual responsible for the fulfillment of the daily needs of the children, maternal death leads to emotional deprivation and also shifts the responsibility of child care to non-parental HIV uninfected members of the family making them vulnerable to discrimination. Also these maternal orphans are deprived of maternal love and affection which plays an important role in shaping the child's personality. Also these children, because of death of their parents loose the confidentiality of their HIV status and become vulnerable for discrimination and stigmatization in the community. As the burden of HIV in the family increases, the psychosocial and economic impact is larger. The number of the individuals infected with HIV in a family (burden of HIV) was ≥3 in 82% of the families. In a study carried out by networks of People Living with HIV/AIDS (PLWHA) in four Indian states, 27% of the respondent had at least one more HIV infected member in the family [2]. This low HIV burden in the family compared to our study could be due to the fact that the survey was conducted in 2003 when National ART service was not started. Now with the availability of free ART services, many individuals in the family with HIV infections are living longer and increasing the burden of the HIV infection in the family.

Because of HIV infection, 56% of these children are living in broken family which leads to psychosocial as well as economic stress on the families. In a study from Kolkota, India in 2011, 33% of them had disturbed relationship with their spouses [4]. Majority of these families have disclosed their status to the other HIV uninfected family members. Though many of these HIV uninfected family members accepted their HIV status (42%), but nearly equal number of HIV infected family members faced acts of discrimination(40%). These acts of discrimination were frequently faced by 34% of these families. These acts of discrimination include physical abuse (26%), refusal to share food (16%), thrown out of their house (14%) and discrimination at work place (14%). These families who faced acts of discrimination coped with them by ignoring them (40%), changing their work place or school (26%) and isolating themselves (20%). More than one quarter of these families felt helpless when they faced acts of discrimination. In socio economic impact study from India, for about 42% male PLWHA and 45% of female PLWHA, the family was supportive. In same study, about 10% of PLWHA who have disclosed their status in the community have reported discrimination mostly in the form of isolation and neglect. They have also been subjected to other kinds of discrimination like – teasing, social boycott, not allowing their children in anganwadi centres etc. They also reported about 10% of the PLWHA faced discrimination at work place [5]. In study from coastal Karnataka, 65% of the extended family members were supportive when the HIV infection status was disclosed to them [3].In a study from China, almost 90% of the caregivers rates their relationships with their family members as poor or very poor [6]. In a study from Kolkota, India in2011, nearly 85% of the families have disclosed their HIV status to the other family members and 15% of them have experienced rejection by them [4]. In a study carried out by networks of People Living with HIV/AIDS (PLWHA) in four Indian states, it was found that 70% of the respondent faced discrimination [2]. In the Thailand study, abandonment by family members and social isolation were the reported frequent changes in the relationship. They also found in their study

that HIV infected families changed their hometown and workplace to avoid discrimination [7].

When these individuals discovered their HIV infection for the first time, 32% had suicidal thoughts, 22% of them were in shock, 19.5% were depressed, 15% each of them accepted and in denial of their infection status. Nearly 10% of them expressed anger towards their spouse and 7% of them felt cheated by them. Similarly when they became aware of their children's HIV infection status, 59% were worried about their children's future, 56% of them felt guilty, 32% of them were worried about their own health which can be detrimental in the care of their children and 24% of them had fear of their child's death. In a study from Kolkota, India in2011, 42% of the respondents blamed their spouses for their illness [4]. In a study from Thailand, found that despair, confusion, a sense of guilt and suicidal thoughts were the emotions expressed by the parents of the child infected with HIV [7]. In a WHO report, it was found that after the diagnosis of HIV infection, many individuals faced large measures of stress and depression [8]. In a study from rural china, found that two third of the caregivers of the HIV infected children were depressed [9].

There was significant decrease in the family's income after the diagnosis of HIV infection. In a study from Kolkota, India in2011, there was significant decline in the family income after the diagnosis of HIV infection especially when the family member was sick [4]. There was also increase in the earning members after the diagnosis which could be due to increased economic needs of the families forcing other non HIV infected family members to earn, due to death of the one or both of the parents or broken family leading to displacement of the families and dependent on extended family members to fill the economic gaps. In a comprehensive 'Socio-Economic Impact of HIV and AIDS' study, sponsored by UNDP and NACO, the work force participation rate of non-HIV children (0-14 years) or elderly (60 and above years) in the HIV households is higher than that of the same age group in non-HIV households [5].

In spite of increase in the earning members, percapita income after the diagnosis was significantly lower than that before the diagnosis of HIV infection. In the socioeconomic impact study, it was found that total loss in income was 9.24 percent of the total household income of all HIV households in the sample [5]. These families' expenditure on medicine increased while expenditure on the non health issues like food and cloth was significantly decreased after the diagnosis of HIV infection. In socioeconomic impact study, it was found that the proportion of food expenditure is much lower for the HIV households, and medical expenses of the HIV households are almost four times higher than the per capita per month medical expenses of the non-HIV households [5]. In another study done in 4 different states of India, it was found that there was increase in the expenditure on medicine and food. Meanwhile, the same study showed decrease in the expenditure on entertainment and education [2].

Though there was increase in the travel to health care facilities frequently, there was significantly decrease in these family's travel expenditure. This paradox was due to the travel allowance provided by the government to reach health care facilities for their ART follow up and decrease in travelling due to social reasons.

Among the few limitations of the study, the recall bias is the predominant limitation. The care givers version of their economic status before and after diagnosis of the HIV infection was not verified. This is an observational study to assess the psychosocial impact qualitatively.

To conclude, HIV infection in the children impact their families negatively. More than half of these

children are orphans resulting the shifting of responsibility of child care to non infected members of the family. This increases the vulnerability of these children as a result of which they face acts of discrimination. These families suffer through various psychological issues due to the HIV infection of the children as well as themselves. There is a significant decrease in the income of these families following the diagnosis of HIV infection.

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