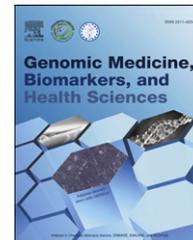




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ORIGINAL ARTICLE

A study of psychosocial problems in families with HIV-infected children in coastal Karnataka

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Abstract Individuals infected with HIV and AIDS and their families have to cope with a multitude of stressors. These chronic and stigmatized conditions can affect the overall functioning and lifestyle of affected children and their families. The aim of this study was to assess the impact of a child's illness on psychosocial issues for parents or caregivers and the problems they face. The descriptive study was carried out at Kasturba Medical College Hospital, Mangalore, India. In total, 27 parents or relatives of HIV-positive children were interviewed after obtaining consent. The male/female ratio of affected children was 0.9:1 and the majority of the children were >5 years of age. Ten children were looked after by both parents, 13 by one parent and four by relatives. The majority of the families had a *per capita* income of <Rs500 per month and a low education level. Of the three children who knew about their illness, two showed behavioral changes. HIV status was known in school for 12 of the 20 school-going children, and discrimination was observed in one case. Family members were supportive in 65% of cases and opposition and fear were the reactions in 30%. Healthcare providers were unsupportive in two cases. Monthly medical expenditure varied from Rs250 to Rs1500. Fifteen children were on antiretroviral therapy largely funded by voluntary organizations. Ninety two percent of the caregivers were aware of the modes of transmission, 85% of the preventive measures and 70% of the complications of HIV/AIDS. In conclusion, in spite of all the efforts raise awareness of HIV, social discrimination and stigmatization persist. General improvements in socioeconomic status and levels of knowledge and well-organized health programs will go a long way in the battle against HIV/AIDS.

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Introduction

Human immunodeficiency virus (HIV), the cause of AIDS, has spread rapidly to every region of the world in the 28 years since its discovery. Each year there are approximately 4.1 million new HIV infections and 2.8 million deaths from AIDS. The number of people living with HIV is increasing owing to population growth and drug treatment, which is prolonging life.¹ It was estimated that in 2008 there were 33.4 million people living with HIV, with children <15 years constituting 2.1 million of these.² While India has an overall prevalence of 0.31%, the Indian state of Karnataka has a HIV prevalence of 0.63%.³ Although intravenous drug use is the major route of transmission in several countries, sexual transmission is the dominant mode of HIV spread globally, with a concomitant epidemic in infants born to HIV-infected mothers.⁴ It is now generally recognized that acute and chronic medical conditions in the pediatric population pose a range of potential psychosocial challenges not only to patients, but also to family members and healthcare workers. Among such conditions, HIV/AIDS present perhaps the most complex psychosocial issues. Overlapping social, individual, family, financial, cultural and illness factors pose a challenge to communities and healthcare teams striving to provide comprehensive services to this population.

Initial interventions in pediatric HIV/AIDS focused on the medical urgency and terminal nature of the disease. Understandably, there was little attention given to long-term psychosocial issues and adjustment. Improvements in medical treatment, however, have resulted in a decline in AIDS incidence and mortality in both children and adults.⁵ These children, who were initially not expected to survive, are now facing academic, social and emotional issues related to living with a chronic health condition.

HIV- and AIDS-infected individuals and their families have to cope with a multitude of stressors. This chronic and stigmatized condition can affect the overall functioning and lifestyle of affected children and their families. Illness and grief interfere with a parent's ability to provide constant care for their children. Owing to parental death and illness, primary childcare responsibilities often fall on extended family members such as grandparents and aunts. In the coming years, there is bound to be great demand for counseling services for families with children affected by HIV/AIDS. Hence, the aim of this study was to assess the impact of a child's illness on psychosocial issues for parents or caregivers and the problems they face.

Methods

This descriptive study was carried out in Kasturba Medical College Hospital in Mangalore, a coastal city of Karnataka, India, over a period of 4 months. The study subjects included parents or caregivers of 27 HIV-positive children between the ages of 1.5 and 12 years. HIV positivity in children is confirmed by three rapid tests after the age of 18 months. HIV-positive children under the care of an ashram or institution lacking a blood-related caregiver were excluded from the study.

At orientation, the purpose, methods and confidentiality were carefully explained to each parent before obtaining

written informed consent. The parents and caregivers were interviewed when they attended hospital outpatient or inpatient departments with their child after obtaining consent. The study was approved by the Ethics Committee of Kasturba Medical College. The data were collected using a pretested questionnaire designed based on a review of studies of psychosocial impact on caregivers. Questions covered: (1) individual information about the child; (2) caregivers; and (3) psychosocial questions. Statistical analysis was performed using SPSS version 11.5 (SPSS Inc., Chicago, IL, USA). Results were analyzed by frequency and percentage, and the Fisher exact test was applied.

Results

The parents or caregivers of 27 HIV-positive children were enrolled in the study. Their demographic parameters are presented in Table 1. The male/female ratio of affected children was 0.9:1 and majority of the children were >5 years of age. Twenty children were attending school, with 16 > 5 years and four <5 years but >3 years. In 37% of the cases, both parents were alive, whereas in 44.4% of cases only the mother was alive. A majority of the families belonged to a lower socioeconomic status and their educational level was low.

Seventy percent of the children were tested because their parents were HIV-positive, and 30% were tested at the suggestion of their doctors. Three children knew about their illness. Of these three, two showed behavioral

Table 1 Demographic parameters.

Parameter	Number (n = 27)	Percentage (%)
Gender of affected child		
Male	13	48.1
Female	14	51.9
Age of child		
>5 y	17	63
<5 y	10	37
Attending school		
Yes	20	74
No	7	26
Caregivers		
Both parents	10	37
Mother only	12	44.4
Father only	1	3.7
Relatives or extended family members	4	14.8
Education of caregivers		
Primary school	11	40.7
Secondary school	11	40.7
Illiterate	5	18.5
Per capita income/mo (Indian Rs)		
<250	8	29.6
250–500	13	48.1
500–2000	3	11.1
Not revealed	3	11.1

changes, one in the form of slow progress in school and the other with loss of appetite. The child's HIV status was known in school for 12 of the 20 school-going children. There was obvious discrimination for only one particular case: the child was made to sit separately in class and received less attention.

Extended family members were supportive in 65% of cases, and in 30% of cases there was opposition and fear (Table 2). In four cases (17%), extended family members were unaware of the patient's HIV status. Healthcare providers were supportive of HIV-infected children and their families in 25 cases. However, in two cases there was a history of discriminatory behavior because of fear of contacting the disease by the healthcare provider.

Monthly medical expenditure varied from Rs250 to Rs1500 (Table 3). Higher expenditure was because of anti-retroviral therapy (ART). Fifteen children were placed on an ART regimen. All children, with one exception, were obtaining financial support from voluntary organizations for ART. All of the children had received modern allopathic measures for their ailments. In two cases, ayurvedic treatment was also being applied. A majority of the caregivers had received professional counseling regarding HIV infection. Six caregivers stated that they did not receive any professional counseling. Most of the caregivers were aware of HIV/AIDS, its modes of transmission, preventive measures and complications (Table 4).

Discussion

HIV infection has become one of the greatest pandemics in the world.⁶ The fight to overcome and prevent AIDS is an example of human resilience, and experience with adequate human support systems will determine the long-term result of this battle.⁷ The aim of the present study was to assess psychosocial problems related to AIDS from the caregiver's point of view. Most of the study families belonged to lower socioeconomic groups. In a cross-sectional study in South Africa, Bachmann and Booyeson compared households affected and not affected by HIV/AIDS and found that the *per capita* income of AIDS-affected households was 50–60% of that of non-affected households.⁸

When asked for the reason for testing the child, 70% stated that testing was voluntary because of the parents' HIV-positive status. This indicates that even though caregivers were from a lower socioeconomic background and had a low education level, most individuals had some level of awareness regarding HIV.

Children are often not told of their own HIV infection status, or that of their parents and siblings. One reason is the fear that the child will not be able to keep the diagnosis a secret. In addition, parents report that they are

Table 2 Response of family members.

Response	Number (n = 23)	Percentage (%)
Support	15	65.2
Indifference	1	4.3
Opposition, fear and shunning of affected	7	30.4

Table 3 Monthly expenditure on child.

Amount/mo (Indian Rs)	Number (n = 27)	Percentage (%)
250–500	4	14.8
501–1000	13	48.1
1001–1500	3	11.1
>1500	7	25.9

uncomfortable and uncertain about how to address questions regarding how the virus was transmitted to the parent and/or child.⁹ In our study, only three of the 27 children knew about their illness. A question for healthcare professionals, along with parents/guardians, to consider is whether or not to tell a child about his/her HIV diagnosis and, if yes, the right time to inform the child. A child's knowledge about his/her own illness and its consequences and complications can be a cause of behavioral changes in the child. Hence, it may be a bad idea to tell the child.

Among the 20 children attending school, the school authorities were aware of the child's infection in 12 cases, and in one case the child was discriminated against.

Stigmatization is an attitude, but discrimination is an act or behavior. When individuals discover that they are HIV-positive, one of the first things they have to decide is whether to tell their family and friends. Approximately 14% of the caregivers interviewed admitted that they have not revealed either their own or their child's HIV-positive status to their extended family members. Moreover, family members were supportive in only 65% of cases. Factors that predict difficulty in adaptation to chronic illness include family stress, cohesion and expressiveness.¹⁰

In the present study, two cases (7%) experienced discriminatory behavior against the child and his/her family at the hands of healthcare providers. According to the report "Future Forsaken: Abuses against Children Affected by HIV/AIDS in India", many doctors refuse to treat or even touch HIV-positive children.¹¹ One reason for such adverse behavior is a lack of sufficient information and knowledge about the infection, its modes of transmission and prevention measures, even among healthcare professionals. It is recommended that clinicians should help in clarifying misconceptions and creating awareness of prevention strategies for this disease.¹²

The monthly medical expenditure varied from Indian Rs250 to more than Rs1500. Owing to the lower socioeconomic status of the participants, this expenditure is substantial. Those on ART were obtaining financial support from voluntary organizations. Yet many of them reported difficulty in arranging money for hospital attendance and for other medical problems. The situation is different in other countries. For example, in a study in the USA, all caregivers were receiving a DCFs subsidy for the child's care, including a medical card.¹³

This was a hospital-based study in which all patients were attending the hospital for their ailments. Two patients had tried other treatment modalities. A majority of the caregivers were receiving professional counseling regarding the infection. Most of them, including those who had not received professional counseling, were aware of transmission, prevention and complications of HIV/AIDS.

Table 4 Awareness of caregivers about HIV.

Awareness about HIV	Received counseling		No counseling received		Total (n = 27)
	(n = 21)	Percentage (%)	(n = 6)	Percentage (%)	
Modes of transmission	20	95	5	83	25 (92%)
Prevention measures	19	90	4	67	23 (85%)
Complications	15	71	4	67	19 (70%)

Fisher exact test, $p = 0.952$, not significant.

The greatest limitation of our study is the sample size, which was small. However, the results highlight many issues that need to be addressed and directions for further larger studies.

In conclusion, in spite of all the efforts to spread information regarding HIV, social discrimination and stigmatization persist among both the general public and healthcare providers. Until the social stigma is totally eradicated, control of the HIV epidemic will remain a distant dream. Financial aspects of medical therapy need to be considered. A larger study including the community will probably shed more light on these issues. General improvements in socio-economic status and levels of knowledge about HIV/AIDS, and well-organized health programs will go a long way in the battle against the disease

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