Status of AIDS Orphans in Chennai, South India

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Short Summary
AIDS Orphans are children who have lost one or both parents to AIDS. In the Indian context, little is known about what happens to these children. This study was planned to assess the status of AIDS orphans. The sample was from a population of HIV-positive patients enrolled in clinical trials at the division of HIV/AIDS of the Tuberculosis Research Center, Chennai, India.

Some of the patients had succumbed to the illness and left behind children. Caregivers of these children were interviewed for the purpose of this study.

This paper discusses the status of 140 AIDS orphans belonging to 67 families who had lost one or both parents due to AIDS.

Abstract

As the AIDS epidemic progresses, there is a shift from focusing on the individual to the family. Often described as a family disease, the AIDS pandemic is leaving millions orphaned in its wake. AIDS Orphans are children who have lost one or both parents to AIDS. In the Indian context, little is known about what happens to these children. This study was planned to assess the status of AIDS orphans. The sample was from a population of HIV-positive patients enrolled in clinical trials at the division of HIV / AIDS of the Tuberculosis Research Center, Chennai, India. Some of the patients had succumbed to the illness and left behind children. Caregivers of these children were interviewed using a semi structured interview schedule. This paper discusses the status of 140 AIDS orphans belonging to 67 families who had lost one or both parent due to AIDS.

Twenty six percent had lost both parents and 50% of the surviving parents were sero positive. Ten percent of the children were sero positive while the sero status of 41% was not known. Their mothers cared more than half of the orphans for, while maternal relatives cared for 24%.

Key words: AIDS Orphans, Caregivers

Introduction

Defined as children suffering the death of one or both parents from the disease [1] the number of AIDS orphans is rising. It is estimated that the total number of children (0-14 years of age) orphaned by AIDS and living at the end of 2003 was 2.1 million to 2.9 million [2]. The number of children in the developing world who have been orphaned because of the AIDS related death of at least one parent will nearly double by 2010 from 13.4 million to 25.3 million according to a report released at 14th International AIDS conference in Barcelona [3].

Researchers noted that the number of children worldwide who are orphaned due to AIDS related causes could be even higher because the statistics did not account for India, which has the second largest number of people with HIV in the world [4].

Since the beginning of the epidemic, well over 2 million HIV positive children under the age of 15 years have been born to HIV positive mothers, and thousands have acquired the infection from blood transfusion or through sex. Since the infected mothers are likely to die of AIDS within 5-10 years of giving birth, the uninfected infants will constitute a growing population of orphans [5].

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The vulnerability of children orphaned by AIDS and that of their family starts well before the death of a parent. The emotional anguish of the children begins with their parent's distress and progressive illness. Eventually the children suffer the death of their parent(s) and the emotional trauma involved [6]. For orphans the stigma of having a parent die due to AIDS complication poses many obstacles. Besides the psychosocial trauma of having lost a parent, many children are unable to discuss their loss with others on account of AIDS being a highly stigmatized disease. This silence may lead to the child feeling isolated and depressed. In many communities, instead of receiving sympathy and care, these children are singled out and treated with suspicion. Many of them are denied access to public health facilities and education; those in foster homes are treated harshly and all too often, abused [2].

Obtaining data on the number of children orphaned by AIDS is difficult but it is believed that the proportion of children in India orphaned by AIDS is far lower than in sub Saharan Africa but because of India's huge population the actual number of children orphaned by AIDS is already high. In 2001 the number of orphaned children was estimated at 1.2 million [7.] The number of children in India orphaned by AIDS is approaching two million according to UN estimates [8](UNICEF, 2004).

Although children are not being orphaned in a large scale in most cities studies have shown that the problem of orphans in some areas of India is already severe[9]. The number of children in India living with HIV currently is far greater than the number of children already orphaned. An increase in orphaning due to HIV/AIDS will not only raises the number of orphans but also will increase the difficulties in meeting the needs of these children. In India there is limited experience in terms of implementing care and support systems for orphans particularly children orphaned by AIDS[10].

While AIDS has often been described as a family disease, there is a dearth of information available pertaining to orphans, from India. This study was undertaken to explore the status of children who had lost one or both parents to AIDS.

Aim: To assess the status of children orphaned by the death of one or both parents to AIDS.

Methods

This study is a descriptive study on the status of AIDS orphans. The study sample was from a population of HIV positive patients who were enrolled in clinical trials at the division of HIV/AIDS of the Tuberculosis Research Centre, (Indian Council of Medical Research), Chennai, India between 2000 and 2003. For the purpose of the study 94 families who had lost a parent due to HIV complications, leaving behind children aged 0-15 years were contacted and caregivers were requested to attend for an interview with the Medical Social Worker. They were briefed on the need for the information, and the time that it would take for the interview.

Caregivers from 67 families responded, and interviews were conducted using a semi-structured interview schedule after obtaining informed consent. For those who were unable to attend in person, information was obtained through a mailed questionnaire in the local language.

Information gathered included socio demographic profile, family size, HIV status of the surviving parent, age, occupation, education of the child, if the child was institutionalized and current health status of the child. Details on who the caregivers were and if more than one caregiver cared for the child were also obtained.

HIV status of the child was obtained from hospital records, and unless it revealed by the surviving parent or the caregivers none of the respondents were directly questioned regarding child's sero status keeping in mind the best interest of the child.

Eligibility criteria

Children (0-15years) who had lost one or both parents to HIV/AIDS were eligible. Caregivers who were willing to spare their time and were willing to give the information required.

Results

Socio-demographic profile of AIDS orphans

One hundred and forty children belonging to 67 families were included in the study. Seventy-two children (51%) were male. Forty-three children (31%) were 1 –5 years of age while 59 (42%) were 6-10 years of age and the remaining 38 (27%) were more than eleven years. Sixty-two children (44%) were from urban areas and an equal number from suburbs, 16 children (11%) were from rural areas. Eighty children (57%) were attending school and had received some education. Only 2 children were employed and 5 had been institutionalized (Table 1).

Sero status of orphans

Fourteen of the children (10%) were known to be HIV positive and of these, 4 had died. Sixty-eight children

(49%) were HIV negative, however the sero status of 58 (41%) children was unknown (Table 2).

Sero status of parents

Thirty-six children (26%) had lost both parents. Fifty-two (37%) had one surviving parent who was already infected with HIV. The parents of 29 children (21%) were HIV negative while the sero status of the surviving parent was not known for 23 children (16 %). (Table 3).

Table 1 Demographic Profile

Sex	No	%
Male	72	51.4
Female	68	48.6
	140	100
Age group	No	%
1-5 years	43	30.6
6-10 years	59	42.2
11-15 years	38	27.2
	140	100
Area	No	%
Urban	62	44.3
Rural	16	11.4
Suburban	62	44.3
	140	100
Education/Occupation	No	%
Attending school	80	57.1
Not going to school	53	37.9
Institution	5	3.6
Employed	2	1.4
	140	100

Table 2 Sero status of Orphans

Sero status of orphans	No	%
Positive	10	7.1
Negative	68	48.6
Not known	58	41.4
Died	4	2.9
	140	100

Caregivers

Most of the children (56%) were cared for by their mothers, maternal grandparents or maternal relatives took care of nearly 24 % of the children while. While 15 % were cared for by paternal grandparents or paternal relatives (Table 4)

Ninety-one children (65%) received care from a single caregiver while 49 children (35%) had more than one caregiver. Caregivers of 50 children (36%) admitted that they had received small amounts of money given by relatives when they had come to visit but there was no consistent support or commitment. However caregivers of 90 children (64%) had to be taken care without any financial help from any other source. The caregivers had reported that 80 children (57%) were in good health, 43 (31%) in fairly good health and 17 children (12%) were falling ill often and their health status was causing concern for them.

Table 3 Sero status of Parents

Sero status of Parents	No	%
Positive	52	37
Positive/died	36	26
Negative	29	21
Not known	23	16
	140	100

Table 4 Caregivers

Caregivers	No	%
Mother	78	55.7
Maternal Grandparents	19	13.6
Maternal Relatives	14	10.0
Paternal Grandparents	10	7.1
Father	7	5.0
Paternal relatives	5	3.6
Institution	5	3.6
Employer	2	1.4
	140	100

Discussion

Socially the death of one or more parents is a devastating event in a child's life and it leaves the child in a pathetic situation and at an age when he or she is most vulnerable. [11] "Care for orphans may be understood as a window to the situation of families and other social networks".

Studies in Rwanda have shown that the majority of new HIV infections are comprised of young people in the workforce [12]. This phenomenon of societies most productive age group falling ill and dying has drastic consequences both economically and socially.

The current study found that most of the deceased parents of the AIDS orphans belonged to the age group between 25 and 47 years, endorsing the widely held conclusion that HIV/AIDS affects the young economically productive age group, leaving behind young orphaned children. In this study, most of the children orphaned were less than 10 years of age.

In a similar study on AIDS orphans done at Namakkal in South India[13], it was found that that about 45% of the children were above 10 years of age, 65% were attending primary school 16% were illiterates and 16% were drop outs.

Another finding that must be addressed is one of HIV testing in children. Caregivers who knew the sero-status of the children had revealed the same during the interviews. Being unaware of the HIV status could be a matter of concern as it influences the health seeking for the children by the caregiver and chances of child being denied proper health care exists.

Both caregivers and physicians must be made aware of the child's sero status in order to make informed decisions regarding the child's health. Children with compromised immune systems are especially susceptible to childhood infections and without proper health care and diet they could face desperate situations[14]. Caregivers who have knowledge and take adequate action could ensure a better quality of life for these children. It is strongly recommended that children with HIV positive parents get tested for HIV [14]. In this study, most children were reported to be in good health while about 12% were facing repeated sickness days.

In the high prevalence district of Kweneng, Botswana an orphan registration exercise conducted in mid 2000 found that only 22% of the people registered as care givers for orphans were employed. The others lacked productive employment, and fully 40% of them were grandparents or elderly relatives. In this study the major portion of the care giving was given by the mother who was the surviving parent.

The current study findings in regard to caregivers also has come out with the finding that caregivers are usually grandparents and maternal relatives. Among the 140 children, 111 were cared for by mothers or maternal relatives.

In a study done at Tanzania on AIDS orphans it was found that 70% of them had lost both parents to AIDS and care giving was mostly by the grandparents, and 60% of the children were in their care. Twenty percentage of the orphans lived with distant relatives and while the rest had no one to take care of them. Scholastic backwardness, lack of shelter, clothes, adequate food and sense of insecurity were some of the problems encountered[15].

This shift of care to the grandparents has been called "skip generation parenting" [16]. In Sub- Saharan Africa, HIV has been dubbed "the grandmothers disease" as the shift of care is increasingly towards this segment of the populace. Studies in Zimbabwe and Zambia found that over 45% of Zimbabwean caregivers and 57%of Zambian caregivers were grandparents [16]. In these studies it was found that over one third of these caregivers were above 60 years of age.

Apart from the problems of taking care of the young at their advanced age, grandparents often face financial constraints as their capacity to earn is greatly diminished and they look for other sources of support. Some of them take care of their grandchildren by getting some form of support by means of shared care or through some amount of financial help from relatives.

A study done to assess the problems of family caregivers found that the primary cause of distress was inadequate

finance to house and care for the children. The government policy of providing higher financial assistance to unrelated caregivers was causing a lot of hardship to family caregivers[17].

Other studies have established that the responsibility for HIV orphans often lay with relatively old and young generations of society[11, 18-20]. In this study 49 children (35%) received shared care while 91(65%) were cared for by a single relative only.

Further caregivers of 50 children (35.7%) received small amounts of financial help from relatives, caregivers of 90 (64.3%) children however said that they did not get any help from other family members.

In our sample it was found that 80 (57.1%) were attending school and 53 children (37.9%) were not in school. This could be due to the fact that 43 children (30.6%) were below 5 years of age.

In Cambodia, a recent study by the Khmer HIV/AIDS NGO Alliance and Family Health International found that about one in five children in AIDS-affected families reported that they had to start working in the previous six months to support their family. One in three had to provide care and take on major household work. Many had to leave school, forego necessities such as food and clothes, or be sent away from their home. All of the children surveyed had been exposed to high levels of stigma and psychosocial stress, with girls more vulnerable than boys.

In the late 1990's a survey of 646 orphaned and 1239 non orphaned children in Kenya found that 52% of the children orphaned by AIDS were not in school compared to 2% of the non orphans. Among the orphaned 56% girls and 47% of boys had dropped out of school within 12 months of a parents death.

Three general observations about AIDS orphans provide a basis for analysis and planning [21]. First, most orphans are not infected with HIV. Second, the orphans create special stress on family and community resources, and third, they are highly vulnerable because families affected by HIV/AIDS usually have more than one ill or dying member.

While many families have absorbed orphaned children out of love, custom or moral obligation, they may not be able to do so indefinitely.

The issue of care is of vital importance in the allocation of funds for AIDS orphans. For the proper development of milestones and for them to be socially responsible adults, more studies are needed to assess orphan children with regard to their psychological upbringing, nutritional status, health status, and monitored so that they can grown up as socially responsible adults.

The well being of children orphaned by the HIV epidemic, like children in distress from other causes, is the test of our future commitment to social stability, economic development and human rights.

Policy makers and health providers must shift their attention to AIDS orphans who are growing in numbers. These orphans are equally entitled to quality care.

While it is fortunate that India can boast of an extended family and others are willing to share the responsibility of child care, it is important that this group of caregivers are also given assistance to help them shoulder the responsibility that is thrust on them. Often, financial constraints prevent these caregivers from giving orphans quality care. They must be made aware of the need to screen the children for HIV, and, if positive, to be attentive to the opportunistic infections that these children are prone to.

Conclusion

This is a preliminary study, which gives a brief profile of AIDS orphans. The study is limited to patients enrolled in clinical trials and therefore not representative of a larger community population. The information gathered was from the caregivers; hence an element of bias could be present. Though there were a number of AIDS orphans among this group only caregivers of 67 families were willing to be part of the study.

Future plans include detailed study and assessment of the children measuring milestones, nutritional status, psychosocial parameters, in order to provide some interventions, which would benefit the children. Caregivers need to be educated on the importance of HIV screening in view of the parents HIV status, and the importance of adequate health care for the children to improve the quality of life.

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