



## A STUDY ON THE CHALLENGES OF HIV POSITIVE CHILDREN IN DAKSHINA KANNADA

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### **Abstract:**

Human Immuno-deficiency Virus and Acquired Immuno-Deficiency Syndrome (HIV/AIDS) epidemic carries with it the forces of destructions. Children are infected with HIV/AIDS through their parents by birth. Children are brought in the families where the situation is such either their parents are ill or they are single parent or orphan. Parents no longer hold jobs, families lose their breadwinners and they use their time and money to care for ill members. This situation has effects on the children's education leads them to discontinue education because of the financial needs of the family. Same situation has been faced by the HIV negative children affected by HIV. Both infected and affected children have to face discrimination from various angles. The main aim of this research is to study the challenges faced by HIV positive children. And the objectives are to study the condition and the problems faced by the positive children and the measures to overcome the difficulties are discussed by the researcher. The information collected by using both from primary and secondary method. Interview is conducted and selected 50 samples and 10 case studies. (1, 3)

**Index Terms:** HIV/AIDS, Health, and Children's Issues, Antiretroviral Therapy (ART) & Transmission

### **1. Introduction:**

Human immunodeficiency virus (HIV) acquired immuno deficiency syndrome (AIDS) continue to pose a catastrophic public health threat reaching crisis proportions among young people. The impact of HIV/AIDS is many more folds on the Children. There are various issues as to be tackled. First if parents are HIV/Positive and alive; if only single parent with positive status; or without parents, Secondly Siblings with positive or negative status; or without sibling, thirdly the child with the positive or negative status. The study is mainly focused on the positive child in the family and the challenges are if one of the parent or both the parents are HIV positive, there will be saviour impact on the child. Children affected by HIV become orphans at the early age and they are forced to work. Children cannot see the parent's situation and they take challenge and work as child labour. And in case children themselves are infected, they have to face double trauma to cope up with their own health issues and to support their parents. Most of the time children are very young to support their family. Whether children are affected or infected they too face stigma in the society like their parents. They are discriminated in all the aspects (13, 14). Parents sickness and their sickness, not even parents can give attention to them, not allowed to do whatever they want in schools, because they are not allowed to play in the ground, their negative siblings are taken care by the relatives and not this positive children's naturally divisions among the sibling, neighbours children are not allowed to play with them and in case of knowing the status they do fun of them and label them, they cannot have food whatever they want, if they are symptomatic and on ART they have to take medicines regularly all this will irritate them. (2, 13, 14)

### **Concept of Healthy Family:**

The concept of family well-being can be seen when the parents perform their duties well in the family. The first and foremost duties of the parents are to provide children the basic necessities of life like food, clothing and shelter. They should keep and protect their children all dangers which are possible to death. They should become the good role model and examples for their children especially mother to the girl child and father to his son. This can be done through avoid bad words, fighting with the partner criticizing children and others. In the healthy family, the children will imitate their parents and parents are like mirror whatever acts you do the children will repeat the same. To become healthy family one should keep a watch on themselves and avoid argument and fight with partners especially in front of children. Teach moral values on what is right? And what is wrong? They should send them to school to get better education and to achieve their goal in life. They should motivate them to get marry and not horrifying about the difficulties of married life. Parents should teach their children the responsibilities after the marriage, responsibilities of a good future father and mother, responsibilities of the good homemaker of the mother and care taker father, to teach them the development of sex and the realities by proper sex education and avoid sex before marriage. They should put values to trust the partner truthfulness and adjustments during the time of happiness and sorrow, to be supportive in success and

failure and healthy and sick. When all these education is parted in the family, the good parenting joy will loving environment can be created and all these aspects in the family will help to feel the member the heaven on earth.

#### **Children and HIV:**

Most often adults are uncomfortable in discussing the sensitive issues such as illness, sex and the death issues. They would like to protect their children from pain and trauma of these issues. They are worried and anxious to know something is wrong with them and their parents. So it is the responsibility of the parents to know the correct age and to explain them the situation if they are not ready to tell, then they can seek the help of the counsellors to tell the situation otherwise the impact will be very bad later because children suffer from HIV disease due to unforeseen circumstances. Therefore, the parents, adult members, community and society are to be held responsible. Can anyone imagine the situation to tell the infant about the HIV infection?

Most symptomatic HIV-infected children do not know that they are infected. They continue to lead normal daily lives. Simple infection control procedures can protect all family members or institutional workers from contracting the virus. Both mandatory and voluntary testing has been advocated to determine the HIV status of orphans. However, there are serious ethical issues involved in testing and disclosure to children. Issues, which need to be determined, include: Who wants to know and why? Will it benefit the child to tested, and how? Who should determine this and how? Can a child give informed consent to testing? Public policy needs to be drawn up in this area to ensure clarity and to protect this vulnerable group. Infants and children with HIV-related illness may have special care needs. Meeting these needs is all the more difficult where one or both of the parent's is/are also infected, or has expired.

#### **2. Modes of Transmission in Children:**

**Mother to Child-Transmission (MTCT):** Transmission is by far the largest source of HIV infection in children below the age of fifteen years. Researcher identified a lady of 21 years who received HIV through parents. Her parents are no more. But she enjoys good health but on ART. Otherwise most of the children are below 16 years of age. Even though the blood transfusion and blood products are regularly screened, and where clean syringes and needles are widely available in health centres and hospitals, mother to child transmission is virtually the only source of infection among young children. The mandatory blood test along with consent form are followed in many hospital, but due to stigma, unawareness and negligence of the parents will not meet the Doctor or go to the same hospital, land only during the labour pain and cannot save the child. There are possibilities to a child who can inherit HIV from infected mother can be in three ways: a). At womb before birth: HIV has been detected much early in the foetus, and in the blood in the umbilical cord. B) A baby can also be infected during delivery by the mother's infected blood or vaginal secretions. This is because during the time of birth the child's skin is very soft and thin, which paves the way for the virus to get into its body. C). The third means of transmission from the mother to child is from breast-feeding. Researchers now believe that the handful of documented cases, where mothers did transmit HIV by breast-feeding was a typical.

**HIV Risk for Street Children:** India is having the highest number of street children in the society. Almost all street children are found in the metropolitan cities and urban areas. They are also the child labourers indulge in various kind of jobs like rag picking, working in hotels, involvement in prostitution, etc. These children are used and manipulated by the adults and there is no support for them to hear their grievance. To live in the society to get basic food, they have to bare all these problems and the street girls are more affected than the street boys. When these children are growing up and in the adolescent period, during this puberty they are no one to guide them, tell and share about the changes which occur in their body. This will be more savour for the girl child who do not have mothers or female relatives to explain to them that menstrual periods are part of normal life, or help them cope with their anxieties.

**Tradition of Devadasi:** The *devadasi* tradition has been a practice in age old in India. This system is generally practiced in low economic group as the religious ritual. The young girls of certain sections of society, economically lower category, were trained as skilled courtesans, and were initiated into the profession through a temple ritual. In some places this custom and tradition is followed even now by offering the girl child to Hindu Goddess Yellamma. In the states of Karnataka and Maharashtra, this tradition exists especially among the poorest among poor group, socially downtrodden sector and in economically poorer of the society. Young girls are offered to the temple priests to assist them in doing the offering service like cleaning the pooja items, getting water, keeping ready the diyas by putting the oil regularly, arranging the pooja items, fluking the flowers in the garden and preparing the garland, assisting in the bajan putting rangoli continues humming the devotional songs, selling pooja items, managing and maintaining the discipline in the surrounding of the temple. But these poor girls are detached from their family, most of the time, were sexually exploited by rich men and others. They are neither given in marriage nor any one show interest in getting married with them. Many of these girl children get infected with HIV.

**Commercial Sex Workers Children:** In most of the families they expect boy child and their attitude towards girl child is not so good or accepted easily. They celebrate the birth of the son and not the daughter. But this is different in commercial sex workers. The mother even she does not want to send her daughter to this business she cannot protect her. First of all she do not have status in the society, do not own her own house, and depend

on the business club, the brothel keeper, and pimps. They welcome the girl child of a prostitute as a potential source of income. The children do not have any status in the society. Father is not known or even known he is not ready to get marry or to give the daughter his name. Not only that nobody is ready to get marry a girl child of the commercial sex worker. The estimated six million children of prostitutes in the country have no other options than to follow the profession of their mothers pursued. Given the present situation of HIV/AIDS in the country, many of these children of prostitutes are likely to be HIV infected either from their infected mothers, or through customers who engage them for sex at very tender ages.

**Rights of the Child Suffering from HIV/AIDS:**

The United Nations Convention on the Rights of the Child (CRC) in the context of HIV/AIDS has spelt out principles for reducing the children’s vulnerability to infection, and for protecting children from discrimination, because of their real or perceived HIV/ AIDS status. Governments need to ensure that the best interests of the children are promoted and addressed. States should include HIV/AIDS, as a disability laws exist to strengthen the protection of people living with HIV/AIDS against discrimination. Take special measures (by the governments) to prevent and minimize the impact of HIV/AIDS caused by trafficking, forced prostitution, sexual exploitation, inability to negotiate safe sex, sexual abuse, use of injecting drugs, and harmful traditional practices. Children’s right to life, survival and development should be guaranteed. Children’s right to confidentiality and privacy in regard to their HIV status should be recognized. This includes the recognition that HIV testing should be voluntary, and done with the informed consent of the person involved which should be obtained in the context of pre-test counselling. If the children’s legal guardians are involved, they should pay due regard to the child’s view, if the child is of an age or maturity to have such views.

**3. Data on HIV Positive Children:**

Worldwide, it is estimated that 17.8 million children under 18 have been orphaned by AIDS, and that this will rise to 25 million by 2015. Large numbers of children across the world become infected with HIV every year. The estimated total number of HIV infections in India was 2.5 million in the year 2006. The estimated number of children living with HIV/AIDS (CLHA) in India is 202 000 according to a UNAIDS report published in July 2004. Half of HIV-positive children die undiagnosed before their second birthday as early testing for HIV is not widely available.

As far as the researcher’s data is concern, researcher identified 50 children from 41 families. (Table No -01), where the children are below 18 years old. Male children are more in number (34) where as girls are less (16).

**Children in the Families:**

Table 1: Total (50 Children) From 41 Families

Age	Male	Female	Total	%
0-5 years	01	-	01	02
6-10 years	05	03	08	16
11-15 years	13	07	20	40
16-18 years	15	06	21	22
Total	34	16	50	100

**4. Early Detection:**

The first step in helping a child who is infected with HIV is to diagnose the child through HIV testing. It is important that HIV-infected children are diagnosed as quickly as possible. Once a child has been diagnosed, they need to be carefully monitored and provided antiretroviral (ARV) drugs, according to national guidelines. Transmission from infected mother to child is mainly prevented by antiretroviral drug (ARV) prophylaxis to mother and baby, replacement feeding and elective caesarean section (ECS). ARV prophylaxis acts by reducing viral load in the mother and as post-exposure prophylaxis to the fetus and baby. Caesarean section before onset of labour or rupture of membranes has been used as an intervention to decrease risk of transmission of HIV.

Disclosure of the HIV status is the process by which a child's HIV status is shared with the caregivers and the child. Disclosure is important for promoting positive living and adherence to treatment. (1,2) Disclosure should be carried out in a sensitive, caring manner. When disclosing the HIV status to the child, the caregiver should consider the following: (a) *Why* should the HIV status be disclosed? (b) *When* should the HIV status be disclosed? (c) *How* much information should be disclosed? (d) *How* should the status be disclosed?

It is important to identify the HIV status earlier. Early detection helps the family to take precautions. Infant it is 18 months or 1 ½ years since their immune system will not develop and difficult to identify the virus. Researcher who have done studies earlier indicates that the early initiation of antiretroviral therapy correlates to a reduced risk of both HIV-related and AIDS-defining illnesses. (1,2) A child’s CD4 count drops below 350 cells/mL is associated with not only more adverse clinical events, but a significant—and even profound—reduction in life years. The early treatment prevents the depletion of CD4 cells, central to the immune response. Once the CD4 counts drops down, and the child becomes symptomatic ie more than two symptoms doctors starts the ART. 82 percent of the respondents are on ART and remaining will have few infections which have been treated.

Table 2: Children on ART (Anti Retroviral Therapy)

<b>Art</b>	<b>Male</b>	<b>Female</b>	<b>Total</b>	<b>%</b>
Yes	25	16	41	82
No	09	-	09	18
<b>Total</b>	<b>34</b>	<b>16</b>	<b>50</b>	<b>100</b>

**5. Health Conditions:**

**Health Stage-Wise Distribution:** NACO (National AIDS Control Organization) has come out with its own staging system. NACO divided the HIV infected in to three stages they are; **Asymptomatic Stage:** In this stage of HIV/AIDS disease no symptoms are visible. **Symptomatic Stage:** During this stage minor signs and symptoms are visible. **Terminal AIDS Stage:** During this stage the HIV infected person succumb to full-blown AIDS with major and minor signs and symptoms due to an array of opportunistic infections (5, 6)

**Major Health Problems in HIV Children:**

- ✓ **Fatigue:** When the virus enters the blood, the immune system is hit. Also, inflammation due to poor immunity causes fatigue.
- ✓ **Joint Pain and Muscle Pain:** Lymph nodes form part of the immune system, when it is infected by HIV virus, the lymph nodes get inflamed. Sore throat and headaches are early signs of HIV.
- ✓ **Skin Rash:** This HIV symptom can appear at an early stage or later stage. If the skin rash is not easily treated then it could be due to the HIV virus.
- ✓ **Nausea and Vomiting:** This queasy feeling which is not easily treated could imply HIV infection.
- ✓ **Weight Loss:** Those with HIV generally lose weight rapidly due to the above symptoms.
- ✓ **Dry Cough and Pneumonia:** If you cannot treat dry cough with common treatments and this persistent coughing can lead to pneumonia, then it is a sign of the HIV virus.
- ✓ **Night Sweats:** Similar to menopausal women, HIV infected individuals also experience night sweats. (5,7)

Other symptoms like Fever, Fatigue, Headache, Pharyngitis (sore throat), Myalgia (muscular aches and pain), Arthralgia (joint pain), Lymphadenopathy (swollen lymph glands). Occasionally, these symptoms will be accompanied by a rash (commonly referred to as an "HIV rash") which manifests with pink-to-red bumps that converge into larger patches, primarily on the upper half of the body. Moreover, 30% will likely experience short-term nausea, diarrhea or vomiting. Most of these symptoms are a direct result of the body's immune response as HIV rapidly disseminates from the site of infection to lymphoid tissues, triggering an inflammatory response. (5,6,7)

Table 3: Health Condition

<b>Health Status</b>	<b>Male</b>	<b>Female</b>	<b>Total</b>	<b>%</b>
Very Good	03	04	07	14
Good	06	02	08	16
Moderate	13	05	18	36
Poor	12	05	17	34
<b>Total</b>	<b>34</b>	<b>16</b>	<b>50</b>	<b>100</b>

**Measures to Overcome Difficulties:** Parent should take care of their infected children. And in case parents are not in a position to take care relatives should give their helping hand to support the family. Majority of the positive parents like to settle their children by admitting them in care and support centre before they die. NGO's which working and providing care is and support will assist them. Parent should take care of the children. (7, 11) In case parents are not in a position to take care relatives should give their helping hand to support the family. Majority of the positive parents like to settle their children by admitting them in care and support centre before they die. NGO's which working and providing care is and support will assist them. Drop-in centers and support programmes, which provide support groups and counseling and education. Care and support centers should help them in providing health care, education and life skill with the support of Government and funding agencies. Children whose parents have died of AIDS related causes often are abandoned by extended family members and rejected by the society. They are ready to take care of Negative children in the family and not the positive children. The main problem AIDS orphans face is the fulfillment of their basic needs like food, clothing and shelter. Experience from different countries show that the best environment for a child is the comfort and home of a relative or, in the absence of one, the home of a foster Family in the child's community.

**6. Preventive Measures:**

**HIV Counselling:** An integrated package of measures consisting of Integrated Counselling and Testing Centre (ICTC), the provision of antiretroviral drugs for HIV. Positive pregnant women should be counselled on infant feeding and support for the feeding method(s) chosen by the mother, can also minimize the chances of HIV transmission among children. (5,6) The choice to breast feed or not, should be made by the mother. The benefits as well as disadvantages must be conveyed to the mother, and she should be allowed to make a choice. Her decision needs to be respected. This package is often referred to as the Prevention of Parent to

Child Transmission Programme (PPTCT) now it is called ICTC. An HIV positive mother should opt for a Caesarean section, which will substantially reduce the chances of the child getting infected during delivery.

HIV/AIDS affects the economic well-being of families, businesses, and societies in many ways. When people become ill and die, society loses not only those people but also their productive potential. They no longer hold jobs, manufacture goods, provide services, or support their families. Families lose their breadwinners; the nation loses people who contribute to the well-being of society. As families use their time and money to care for ill members, their energies are diverted from working to provide income or farming to provide food. Not only the present but also the future is affected, as family members discontinue education because of the financial needs of the family. Even burying the dead makes life more difficult for families and society. Funerals are costly, and people miss days from work to attend the rituals. The epidemic's high death toll is producing cultural changes. In some communities with high rates of HIV infection, cemeteries have become overcrowded, creating pressure to accept practices not previously sanctioned by religious and cultural authorities, such as cremation. Funerals are a visible, potentially numbing reminder to all that a deadly disease threatens their survival.

**Schooling and HIV Education:** Children should be given age-appropriate, culturally relevant, scientifically accurate and non-judgmental education and information about sex, HIV, AIDS and relationships. The inclusion of sex and HIV & AIDS education for young children is vital for tackling the stigma surrounding HIV, and to teach others the facts about HIV transmission. 16 HIV-awareness programmes are important to encourage openness about HIV rather than silence. 17 There are many ways to reach young people; including through social groups, the media, and peer outreach - not just at school. In addition, all children living with HIV have the right to attend school, just as any other child does. Policies need to be in place to ensure a child living with HIV at school is not subjected to stigma and discrimination or bullying, and that their status is kept confidential. (20)

**Child Rights:** Children and adolescents are sharing an increasing burden of the global HIV epidemic. HIV prevention programmes can tackle this issue by ensuring children's rights within society are granted. This includes the right to education, contraception, involvement in HIV programmes, safety from violence, gender equality and a lack of stigma. (21)

**Preventing Child Marriages:** Globally, around 11% of young girls are forced into marriage before the age of 15. This puts young girls at risk of HIV, as they may be unable to negotiate condom use, or prevent sexual violence. Early motherhood also risks a young girl who may not know her HIV status passing HIV to her baby. (21) HIV prevention programmes need to reach young girls who are forced to marry early.

**Family Support for Children Living with HIV:** Supporting a family holistically can be the best way to ensure a good quality of life for the child. This should include social protection schemes that provide external assistance to poorer families in areas where HIV prevalence is high. Such schemes are now seen as a valuable part of improving the lives of children affected by HIV. (24)

**Financial Support for Children Living with HIV:** Reduced household income combined with increased expenses (for example for treatment, transport, funerals) can push families into poverty, which has negative outcomes for children in terms of nutrition, health status, education and emotional support. By reducing a household's economic vulnerability, children benefit from better nutrition, the opportunity to go to school instead of work and better access to healthcare. (14, 25)

## **7. Measures to Overcome the Problems:**

Strategies to cope up:

- ✓ A holistic approach which include both nutrition and health services should be adapted to help the HIV positive Children.
- ✓ The reduction of infant mortality and positive children's birth should be avoided by taking precautionary measures.
- ✓ Proper awareness should be given to HIV positive parents, pregnant and lactating women with the health of infant and young children. Alternative breast feeding method to prevent from further transmission of HIV virus.
- ✓ In view of the high risk of malnutrition and disease that HIV positive children face at all the three critical stages viz., infancy, childhood and adolescent and focused attention should be paid to meeting the nutritional needs of positive children's at all stages of the life cycle.
- ✓ Children whose parents have died of AIDS related causes often are abandoned by extended family members and rejected by orphanages. They are virtually unnoticed, ignored and left to fend for themselves. The main problem AIDS orphans face is the fulfilment of their basic needs like food, clothing and shelter. They are often deprived of other needs like education, psychosocial needs. Property rights of these children are ignored. Very many of them turn to streets where these children will go when their parents die or fall sick.
- ✓ The psychological needs like love, care and concern as to be provided
- ✓ Funding, technical assistance and support programmes that act as umbrella structures to channel funds and provide technical assistance. Advocacy and community mobilisation groups that protect the rights of individuals and facilitate access to health and welfare services and schooling.

- ✓ Drop-in centres and support programmes, which provide support groups and counselling, education and often have an income generating activity.
- ✓ A family or Cluster Foster Care programme has been initiated where a surrogate mother is identified and hired to care for six orphans in the community. She is provided with a home, in which they all live, and she raises the children as though they were her own. Foster care grants are accessed to pay for school fees and uniforms, and the foster receives a stipend.

### 8. Conclusion:

Social parenting in the context of care and support to AIDS orphans. India's AIDS orphan crisis cannot be effectively dealt with unless and until the society rises up to the occasion. The future of millions of these children is in the hands of the community itself. The community cannot shrink from its moral responsibility to care for these children saying, "it is the responsibility of the government". We cannot go on with the funding from outside. The community has to find out resources to meet the expenses of the children within the community. With hope we await the time to come when people say, "these are our children and we will look after them".

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