

## Children Living in HIV Families: A Review

Md Shahidul Islam<sup>1</sup>, Victor Minichiello<sup>2\*</sup> and John Scott<sup>3</sup>

<sup>1</sup>School of Health, University of New England, Armidale, NSW 2351, Australia

<sup>2</sup>Emeritus Professor, University of New England & Adjunct Professor, The Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne, Australia

<sup>3</sup>School of Justice, Queensland University of Technology, Brisbane, Queensland 4001, Australia

### Abstract

This review article summarizes the current knowledge about children born or living in families affected by HIV, a topic of recent interest in the HIV field. It also presents a case study of a child's narrative about the implications of living with a HIV parent. The case study is part of a larger study involving both parents and children living with HIV in Bangladesh. The paper discusses the implications of HIV for children, their families, and social services to gain a better understanding of some of the social issues, such as stigma, associated with this illness. The paper recommends that the development of effective social and service interventions using appropriate language, information, and access to social support services are urgently needed to reduce the concerns and increase the life opportunities of children living in HIV families.

**Keywords:** Children; Parents; HIV; Family; Stigma; Bangladesh; Social services

### Introduction

The Human Immunodeficiency Virus (HIV)/Acquired Immune Deficiency Syndrome (AIDS) is a major public health concern with health and social impacts. So-called "risk groups" were the target of early public health interventions in the West and continue to be highlighted in public health discourses. Children, perhaps because of the association of the virus with sexual behaviors and drug use, have often been overlooked in public health discourses associated with HIV [1-3]. However, worldwide, children comprise a sizable number of new infections. While there has been a worldwide decrease in new HIV infections among children in recent years, largely due to improvements in access to services preventing transmission of the virus from mother to her child during pregnancy, labor, delivery, and during breastfeeding, it is estimated that approximately 1,000 babies are infected through mother to her child transmission worldwide each day [4,5]. Recent data suggests that nearly 3.3 million children aged 0-14, and 2.1 million adolescents aged 10-19 are living with HIV [6]. According to the latest United Nations International Children's Emergency Fund (UNICEF) report, approximately 15.1 million children under the age of 19 lost either one or both of their parents to HIV/AIDS or other associated causes [6]. HIV and AIDS regional summary indicators are outlined in Table 1 [6]. Data further suggest that 150,000 children under 15

years of age are living with HIV in the South Asia region, along with 780,000 children who have lost one or both parents to AIDS [6]. In Bangladesh, the focus of the current research, the estimated number of adults and children living with HIV was 9,500 [4,100-97,000] and HIV prevalence among young people (15-24) is below 0.1% [7]. This paper will provide a brief review of some of the key issues currently identified in the research literature. The literature was collected using a number of search engines which included Proquest, Pubmed, Gale, CINAHL, Google scholar, Sociological Abstract, and Web of Knowledge.

The key words for the search were HIV, AIDS, HIV-infected/positive people/parents, HIV-infected/positive/affected children, HIV stigma and discrimination, families, Bangladesh, and South Asia. The key themes found in the literature centre around issues relating to psychological and physical problems, social stigma and discrimination, poverty, and quality of parent-child relationships, and these are briefly summarized below.

### Key themes in the research literature

HIV may be particularly challenging for children in a family with HIV-positive members [1,8]. Children born into HIV-affected families have reported numerous psychological and physical problems, including fear, isolation, depression, anxiety, grief, low self-esteem, and trauma [9-18]. It is now recognized that children living in HIV-affected families also face multiple social adversities, including the disruption or loss of parental care and support, increased poverty, loss of income, malnutrition, withdrawal from school, decline in school enrolment and attendance, decreased access to health care, increased participation in household activities, as well as increased risks of abuse, exploitation, and HIV infection [1,12-15,19-27]. In a recent study, Sherr et al. [17] demonstrate that children who were born into a family affected by

	Aged 0-14	Aged 10-19	Children who have lost one or both parents due to AIDS
Sub-Saharan Africa	3,000,000	1,700,000	10,600,000
Middle East and North Africa	14,000	17,000	610,000
South Asia	150,000	130,000	780,000
East Asia and the Pacific	63,000	110,000	830,000
Latin America and the Caribbean	56,000	82,000	260,000
Central Eastern Europe/ Commonwealth of Independent States	19,000	22,000	7,600,000
Least developed countries	1,500,000	900,000	17,700,000
Low- and middle-income countries	3,200,000	2,100,000	17,800,000
World	3,300,000	2,100,000	15,100,000

**Table 1:** Estimated number of children aged 0 to 14 and 10-19 living with HIV and children who have lost a parent due to AIDS: Regional summary.

**\*Corresponding author:** Victor Minichiello, Emeritus Professor, University of New England & Adjunct Professor, The Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne, Australia, Tel: +61 439 774 099, E-mail: [vminichiello56@gmail.com](mailto:vminichiello56@gmail.com)

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HIV experience problems related to health, cognitive development, education, and exposure to sexual risk behavior. They identified social stigma as the key determinant of negative outcomes for children in HIV-affected families.

It needs to be noted, however, that children may experience HIV stigma and discrimination with varying intensity and in several ways. For instance, a quantitative study conducted by Surkan et al. [28] showed that about 32 percent of children felt discriminated against due to their parent's HIV-positive status in Haiti. This study also found that place of residence, lack of social support, and caregivers' HIV-related stigma of HIV-positive parents were closely related with discriminatory attitudes towards HIV-affected children. Another study conducted on 147 mother-child dyads reveals that children of HIV-positive mothers were less well-adjusted than children in a non-HIV parent sample [29]. Due to poor health, many parents cannot provide the care necessary for physical and psychological development for their children in their early years [17,30].

Stigma may be more intense when poverty is an issue as it may impact on access to school, services, and employment opportunities for these families and their children [11,17,27]. In a more recent study Sherr et al. [17] indicate that children affected by HIV and AIDS experience major social adversities in the context of poverty. In some nations, poor infrastructure and limited access to basic services can accelerate the impact of HIV/AIDS on children and families in a number of ways [27,31,32]. For example, children living with HIV-infected individuals are often required to take over the parenting role [10,33]. Children of HIV-infected parents need to care for infected parents and younger siblings [34]. Assuming the parenting role hinders the natural development of the children, as they miss out on fulfilling familial responsibilities and roles appropriate to their age [24,34,35]. This is also linked to increased experiences of low self-esteem and social isolation in childhood [36].

The quality of parent-child relationships is important in family life, and the stigmatizing nature of this life-threatening disease can seriously complicate these relationships and life opportunities [12,17,23,25]. Some research has found that HIV-infected parents have poor quality relationships with their children compared to non-infected mothers, while high quality mother-child relationships are important for the enhancement of psychosocial functioning of children [20,27,37]. A study of children aged between 11 and 16 years with HIV-positive mothers showed that these children had more difficulties in their relationship with their mother [38]. Studies have identified that a poor parent-child relationship can also lead to psychological problems among children with HIV-infected parents [20,39,40]. The death of parents due to HIV often has negative effect on children's experience of childhood and academic achievement, especially in developing countries [15-16,41,42]. As indicated by some studies from developing countries, children of HIV-positive parents experience lower school enrolment and attendance, and higher rates of school dropouts [41,42]. There is increasing evidence from the developing world that children of HIV-positive parents experience increased mental health and behavioral problems [43-45].

In spite of ample evidence that HIV/AIDS profoundly affects children in families, not enough systematic research has been outlined to illustrate the nature and extent of the problem and how it relates to other key sources of disadvantage for children. Although there are plenty of sociologically relevant accounts of children's issues in relation to HIV/AIDS, there are few studies investigating children's experiences in their daily lives. Research that has been done on children is largely

quantitative [25,26,30,46,47], rather than qualitative in design, which makes it difficult for researchers to offer an in-depth account of children's lived experiences. Encouragingly, there is a small but growing body of literature on the experiences of HIV-positive children; however, these are only relevant to economically developed countries [25,26,30,47,48]. A research agenda is emerging that investigates the experiences of children in HIV-infected families from the perspectives and narratives of children, although this can sometimes pose issues for research ethics committees, especially associated with consent [25,26,47].

Within the context of the limited studies conducted on HIV/AIDS in some countries, such as Bangladesh, including listening to the stories of children living with and affected by a parent with HIV, we conducted a larger study, involving in-depth interviews with both parents (either mother or father) and children (HIV-positive or -negative) living with HIV in Bangladesh, to better understand the needs of HIV-affected children [49]. The case study described below was selected to sensitize those who work in the HIV field to the complex social issues impacting upon children living with HIV parents.

### Case Study

The larger study involved in-depth interviews with 19 HIV-positive parents and their 19 HIV-negative children as a dyad. Participants were recruited with the support of two self-help groups of HIV positive people, in two settings, namely Khulna and Dhaka in Bangladesh. The study explored how the experiences of parents and children are influenced by a variety of factors and living conditions [49]. During the interviews, children shared their experiences of living with HIV-positive parents within the family context of Bangladesh. The results demonstrated that they were rejected, mistreated, insulted, and discriminated against directly and indirectly by extended family members, peers, and community members because of their parents' HIV-positive status. Almost all of them isolated themselves from their peers due to fear of stigma and discrimination. Their social development, including academic achievement, was hampered by their parents' HIV status through a number of processes such as unsupportive environments, economic hardship, gender roles, increased household responsibility, discrimination, and negative thoughts and feelings. While each child's story is different, a case study of a child (Rafik: Pseudonym) has been selected to portray the lived experiences of children, making sense of their lives in such life threatening and complex situations. The case study aims to provide a voice to the issues highlighted in the literature review.

Rafik, a 15-year-old boy, lived with his HIV-positive mother. His father died from HIV related-complications. He was younger than his sister, who was married and lived with her husband. Rafik was HIV-negative, and enrolled in the ninth grade at the time of the interview. Rafik began by describing the enduring emotional impact of having parents who were HIV-positive.

*I was a child when my mother contracted HIV. I can't remember my father's death; I can't even remember his face. I have been watching my mother suffering from this disease since my childhood. It was very painful to me. Still it makes me upset.*

In the conversation, Rafik indicated that he missed his father daily. He also compared his experiences with those who have a father in the family. The following quote highlights the significance of the father as family "breadwinner" and the consequences of loss of a father.

*If my father was alive my mother would not have to work hard. When all other families are led by the father, our family is maintained by my*

*ill mother. It is really painful. If my father was alive I would not have to think about my education expenses. Without my father my family is incomplete and it is difficult for my mother who has to work hard. My friends have their father with them but I haven't. There is not much need in their families. This makes me so upset.*

Rafik described the impact of HIV on his family. Notably, his narrative gives us clear insights into how he faced problems in the community due to his parents' HIV status. He further described that he was mistreated in the community for being associated with an HIV-affected family. HIV was understood and described with reference to old Bengali terms which have strong moral meanings and imply social transgression on the part of those to whom they are applied. In the interview he indicated that community members believed that they had contracted *kharaprog*<sup>4</sup> for which they were rejected from the community. He described how his father was called *kharaplok*<sup>5</sup> (literally translated as "bad person") for having HIV contraction by *kharapkaj*<sup>6</sup> (literally translated as "bad practices"). Children of parents with HIV faced social ostracization and exclusion from everyday social activities based on their parental status. In this way, stigma, drawn from the status of an individual family member, was transferred to the immediate family members.

*I have faced problems in my community previously, due to HIV. People thought that as my mother is infected with HIV, we are also infected with this disease. When I was a child people asked me, does your mother have AIDS? Then many children did not play with me. Someone said, "Your mother has kharaprog; you also have kharaprog, don't come to us and don't play with our children." Our neighbors said that our father was a kharaplok. As he did kharapkaj in India so he became AIDS patient. From him your mother caught this disease.*

Rafik recounted vivid incidences of when and how he was rejected by some children as well. Rejection could be experienced as verbal taunts and physical isolation.

*Some children of our locality used negative language. They asked me if my mother was suffering from AIDS. How did my mother come to be affected with this disease? Why did your father die? Listening to these comments, I became upset. Many of them avoided me. If I called someone they did not come and talk to me.*

Rafik described the problems he faced in school due to his parents' HIV status. For example, he indicated that he had been threatened by some children at school. He also mentioned that peers assumed that he was also HIV-positive, and therefore, meeting with him at school would put them at risk of contracting HIV.

*I don't face many problems in school nowadays. People from the office (self-help groups) talked with school teachers. All the students are not aware about the disease of my mother. Students from my locality who knew told others about my mother's disease. Watching me they talked among themselves. Many students treat me negatively. They said, "You will not come to school. If you come to school we will hit you. You have AIDS. If you come to school we will be infected with this disease.*

<sup>4</sup>When community members referred to their HIV status as *kharaprog* they specifically meant that the informants had contracted it via extramarital sexual relations with sex workers.

<sup>5</sup>In the context of sexuality, men who have been engaged in sexual relations outside of a heterosexual marriage are considered *kharaplok*.

<sup>6</sup>When other people referred to *kharapkaj* they specifically implied sexual promiscuity or, more particularly, that people had extramarital relations with sex workers.

In addition to the support of self-help groups, cited above, Rafik noted that his teachers support was helpful when students mistreated him. However, assistance was limited and could not be extended to all social spheres.

*When students misbehaved towards me, I told this to my teachers. Teachers scolded them. After that they did not say anything at school, but they said these things outside of the school.*

Rafik commented that his sister faced more problems in school than him. He highlighted that a variety of factors that included potential financial crises, the influence of his mother's illness, future uncertainty and gender norms, forced his mother to get his sister to marry at an early age.

*But my sister faced more problems before. So my mother managed to get her married earlier. My sister got married when she had completed year ten education. After that she did not study more. The family financial crisis she meant that could not continue her education. Besides, my mother was ill, and it was her responsibility to give her in marriage. For this reason my mother got her married, though she did not cross the marriage age.*

Rafik described the techniques he used to conceal his mother's HIV status from his friends in school.

*But when I grew up and went to high school, I made some friends who loved me. I convinced them. They could understand the matter. I never told anyone that my mother has this disease.*

Rafik's story revealed that he was scared for the future uncertainties and insecurities of his life. He was particularly worried about his mother's illness and his education.

*I am really scared about my future. My mother is ill, but she works very hard. If anything happens to her then what will happen to me? Who will look after me? How will I continue my study? I have no-one except my mother. So when I think about this I become upset.*

From the foregoing case study, it is clear that the Rafik was affected directly and indirectly by parental HIV contraction. His everyday activities were overshadowed by the socio-economic and socio-cultural consequences of his parents' HIV status. His story reveals that Rafik faced several psychological consequences of having HIV-positive family members. He felt upset that his mother had been diagnosed with HIV. He was overwhelmed with anticipatory grief as he felt worried about losing his mother. He constantly felt unnerved by his thoughts that his mother would die and about the potential impact of the events that would overtake him. Being a child of single parent Rafik was more upset because of his concern over who would care for him when his mother died. The future was bleak. He indicated that his parents' HIV status had affected his life largely through the reduction of income due to his father's death. In terms of social impacts, Rafik was subject to social exclusion from everyday activities such as play and in more formal settings such as school. This exclusion could be experienced in terms of physical isolation and in terms of direct and indirect (gossip) verbal ostracism.

### **Some implications for children, their families and social services**

What do we know from the existing literature and confirmed by this case study is that there can be no doubt that children's lives are affected with the illness of their parents, but when the illness carries social and



moralistic connotations, the impact is much greater in intensity and consequences with respect to social interactions. Notably, a parents' HIV-positive status has a significantly negative impact on children's mental and psychological wellbeing [17,23,50]. For example, Cluver and Gardner [43] reported that children felt high levels of psychological distress after learning of their parents' HIV diagnosis and face more mental health problems including depression, anxiety, and fear [10,27]. Children in an HIV-affected family demonstrate lower self-esteem and, as mentioned by Rafik, possible social isolation from the community which can impact on the life chances of these young people. Some of these impacts, such as being teased at school, can have long term adverse impacts on self-image and life opportunities.

Recent evidence suggests that these implications are so pervasive for HIV-affected children, especially those who experience multiple adversities, i.e. physical, psychological, and social in the context of poverty [27], that social services are urgently required to support this population group. Rafik would have benefited from access to financial and material support, assistance to deal with psychological issues arising at school from a school counselor, medical teams taking into account counseling, and medical care of children who have HIV positive parents so that he can develop better mental health coping strategies, and access social support and community services. Interestingly, in Rafik's story health professionals were not mentioned nor did he give the impression that it would be appropriate for someone in his situation to have the right to seek such care. In this way, his experience of HIV within the family is constructed as a social rather than a health or biomedical problem. The primary sphere in which he experiences stigma associated with HIV is the school setting where he spends much of his everyday life and experiences most social interaction.

The Economic Intelligence Unit commissioned by UNICEF conducted a nine-country review in the Asia and Pacific region, including Bangladesh, to gain a perspective of the extent to which children and households were affected by HIV. In regards to national social protection frameworks, the reports show that social protection criteria are moderately maintained for the benefit of affected children in Bangladesh [4]. In Bangladesh social protection is treated as social security and services. Considering that the Western child-benefit model, in which the children get social support and facilities/services from government, is not common in Bangladesh, children are compelled to seek support as they became more dependent on others. For instance, in the foregoing case study, Rafik could have been urged and better supported to seek help with his educational institution. Increasing HIV-affected children's access to social protection may be an effective strategy for reducing children vulnerabilities in Bangladesh [51]. Significantly, government and different non-government organizations can play an important role in providing support for children born into families affected by HIV. Governments should be more attentive and take more direct action in relation to the social and economic welfare of children. For example, a home care centre can be formed for the orphans of HIV parents. Such initiatives are at present absent in Bangladesh and many other countries.

As with other developing countries, Bangladesh lacks basic services including health and welfare services for the physical and mental benefit of HIV-affected and disadvantaged children. Therefore, appropriate intervention programs must be developed and further strengthened to prevent mental health problems arising among HIV-affected children. Children suffering multiple adversities should be targeted for multidimensional interventions, such as social development, psychological, familial, and normalization of the child within their

communities to lessen stigma [27]. While Rafik's teachers intervene to prevent him being bullied by peers, they did not refer him to support services which have the potential to address the psycho-social impacts of stigma. But in a study Stein et al. [27] outlined that such services are only available in high HIV-infected and affected countries in Africa.

Several studies have highlighted the importance of more effective evidence based and family focused interventions for HIV affected families and children [10,11,24,52]. For example, in a recent study Betancourt and colleagues [10] advocated that family strengthening intervention is an effective intervention for promoting healthy family functioning and reducing mental health problems among HIV-affected children in low-resource settings, which acts through quality parent-child relationships, and family communication and parenting skills. While such family-based preventive interventions are available in Sub-Saharan Africa, these are currently unavailable in Bangladesh and many other developing countries. It is essential for the promotion of children's well-being that when community actions are planned there is community involvement in decision-making, policy development and program implementation [53]. This may be useful not only at a practical level of program implementation and design, but also in terms of preventative efforts, as stigma is a product of community interactions and therefore needs to be addressed at a whole of community level. In some circumstances the involvement of children in designing such programs could be very useful and empowering in overcoming the stigma they may face in the community [52]. This is especially so because, as noted above, children experience stigma in terms of everyday interactions, such as play, which are highly contextual, and community and culturally specific.

The financial burden and economic decline of family income due to HIV was highlighted in our case study as well as discussed by other researchers [54,55]. In particular, Alkenbrack et al. [54] indicated that monthly household income of HIV-affected families was 47% lower than non-affected families in Cambodia. In another study of families in China, Shao-ru et al. [56] showed that the income of 93.3% of HIV-affected families decreased by more than 30%. Considering that Bangladeshi fathers are most often the main (and sometimes the only) source of family income, the death of the father brings with it severe economic hardship and a significant reduction in opportunities [17,27,57]. This has also been confirmed by the narrative of Rafik, as he stated that his father's death resulted in severe hardships in his family. Therefore, programs should include financial assistance to cope with economic hardship, and enhance support for access to education, and other basic services for the HIV-affected children. In particular, a scheme that assists such families with the cost of books, and other education costs would be helpful, including providing additional social resources that offer resilience skills.

In addition, social protection programs for poor and vulnerable HIV household can increase the and capacity capacity to cope among HIV-affected children [51]. In Bangladesh children rely on parents for care and protection. Family resources play a vital role in protecting children from adverse consequences of illness. In a recent study Stein et al. [27] contend that "young children in particular need a continuous and predictable attachment to develop their psychological and interpersonal capacities, to feel supported and safe, and to be protected from being overwhelmed by threatening events". But HIV infection in a family disrupts the supportive capacity of the family, and potentially leads children into insecurity and uncertainty, as mentioned by Rafik in the case study. In these circumstances, extended family members and/or economically solvent and powerful community members may come

forward to provide support care for these vulnerable children.

In developing countries, the father's death can have significant impacts on children's education and social development. It can lead to absenteeism, and in some cases, children leave school altogether [15], which only further entrenches longer term hardship and poverty. This is particularly salient in single parent (widows) families [17]. For example, Rafik indicated that being a child of a widow he felt worried about his education as his sister could not continue her study as a result of financial crisis. As a consequence, interventions that facilitate the education of children of HIV-positive parents should be prioritized [21]. In doing so, parents living with school-aged children could be assisted to cover school fees and other costs associated with schooling to foster their children's future development. Children living in female-headed households could also benefit from interventions designed to improve their economic development.

Our larger study, and this case study, show that community members did not like interacting with HIV-positive people and their children because of their fear of being infected. The nature of fear of HIV in Bangladesh is culturally pervasive [58-60]. HIV, because of its links to morality and culturally specific normative frameworks, is conceived as a highly polluting disease which is experienced at a biological and social phenomenon. It is essential to formulate appropriate intervention programs to educate people and minimize stigma and discrimination towards HIV and AIDS. Schools could play a vital role in creating awareness among students about HIV and AIDS. As shown in our case study, schools are an important social arena for young people and education can be a rich resource to provide optimism for the future and opportunity to break cycles of poverty. In a country such as Bangladesh, teachers and religious leaders can play an important role in humanizing the face of HIV and its impact on the lives of children, as Rafik described that the situations had been improved after consultation with the teachers in the school. Likewise, involving religious leaders can be effective in providing HIV and AIDS information and increasing the acceptability of the initiatives in Bangladeshi society, especially given the strong moral associations with the virus which associate it with "bad" or polluted identities. This noted our research also indicates that the school environment can also entrench the experience of stigma when both teachers and students are ignorant of HIV [61].

In addition, peer support and affiliations at school may also be emotionally beneficial as mentioned by Rafik who sought support from friends to cope with stressful situations. Young children listen and learn from peers and get easily motivated by each other and therefore, awareness building through peers such as, forming peer groups or youth clubs at the schools can play a key protective role in the lives of HIV-affected children. It is important for policy makers to design programs that use culturally appropriate language, books, and films that sensitize children to the hardship created through misinformation and discrimination. Although some culturally appropriate programs and initiatives have been taken, for example, the most popular TV advertisement "*bachte hole jante hobe*" (to live to know) provides HIV prevention information to young people, none of these interventions convey the message about stigma and discrimination faced by HIV-affected children, and in changing attitudes towards these vulnerable groups [62]. Advocacy and sensitization programs targeting various groups such as planners, policy makers, teachers, religious, and community leaders could be formulated to change people's perception towards the children born into families affected by HIV.

## Conclusion

The implications for the delivery of innovative services to support children living in HIV families have been highlighted in this paper. An important step in giving these issues much greater public space is taking place and this political recognition is significant in the allocation of funding to allow such services to be established and delivered to clients. More importantly, such discourses may remove the stigma associated with HIV and therefore allow families affected by this illness to come forward and discuss their concerns and seek appropriate interventions. For example, in 2007, the importance of the well-being of children in HIV-affected families was recognized in the progress assessment of the Millennium Development Goals (MDGs). Likewise, world leaders, during a 2011 meeting of the United Nations General Assembly, committed to work together to achieve a 90% reduction in the number of new HIV infections among children. However, in order to achieve these goals, it is necessary to more actively engage children and their families, and the communities they live in. This means better understanding the social issues that affect such families, as discussed in this paper, and more importantly, from the perspectives and experiences of the children.

What is urgently required to help children such as Rafik is the development of innovative interventions using language, information, and access to social support services that reduce their concerns and increase life opportunities for this population. Children should be seen as important stakeholders in this debate and, at least, inform the development of strategies that empower them to cope with living in families with HIV. Many of the interventions we suggest are more social and attitudinal than medical. Medicine has made significant advances in assisting people live longer with HIV. Now we need to focus our attention on how we can make the lives of people, and children, affected by HIV entering into families equally a less socially disruptive event through knowledge that promotes information and interventions that both significantly lessens stigma and empowers children living in HIV families. 'Now we need to focus our attention on how we can improve the lives of children affected by HIV through knowledge that promotes interventions that significantly lessen the stigma associated with HIV and empowers children and their families.

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