



Published in final edited form as:

AIDS Care. 2011 July ; 23(7): 873–879. doi:10.1080/09540121.2010.542123.

Experiences of families caring for an HIV-infected child in KwaZulu-Natal, South Africa: An exploratory study

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Abstract

In South Africa, 2.5% of children are living with HIV. KwaZulu-Natal is the province most affected by the epidemic and has the highest number of pregnant women living with HIV. This study reports on a qualitative study to assess the views and experiences of those involved in caring for a child with HIV/AIDS. In-depth interviews were conducted in KwaZulu-Natal with 13 women who were the primary caregivers of a child with HIV/AIDS and 12 key informants who worked with children and families living with HIV/AIDS. The combination of widespread poverty and HIV-related stigma was perceived to compromise the health of a child with HIV/AIDS. Caregivers' primary focus was on economic survival and there was little income to meet basic human needs including the child's. Stigmatizing attitudes caused some caregivers to keep their child's sickness a secret and symptoms were sometimes ignored or treatment delayed. Little material and emotional support was available to caregivers who were overwhelmed by multiple stresses in this context. Support group interventions for caregivers of children with HIV/AIDS can be a useful resource provided that they jointly address the economic and psychological needs of caregivers. A stronger commitment at the national level to reduce poverty and HIV-related stigma is needed to strengthen the capacity of families who are caring for children with HIV/AIDS.

Introduction

In recent years the literature on children and AIDS in South Africa has focused largely on AIDS orphans (Cluver & Gardner, 2007; Cluver et al., 2009). Not as much is known about another group of children impacted by the epidemic, HIV-infected children, and the experiences of caregivers of these children. Recent estimates indicate that 2.5% of children 2–14 years old are living with HIV in South Africa (Shisana et al. 2009). For 2009, the total number of new HIV infections in South Africa was estimated to be 413 000 including 59 000 among children (Statistics South Africa, 2009). KwaZulu-Natal is the most affected province in South Africa and recent estimates showed that it had the largest number of pregnant women living with HIV –37.4% (Shisana et al. 2009). The majority of caregivers of people living with HIV/AIDS in South Africa are women and the demands of caregiving are exacerbated by extreme poverty, stigma, lack of support and responsibilities for other members of the household (Orner, 2006). As the epidemic has worsened over the years, the health care system and social service system in South Africa has become overburdened (Walker, Reid and Cornell, 2004). Consequently, the responsibility for care has fallen mainly on families (women in particular) and they in turn have struggled to adapt as more and more family members have become sick and there are too many children to care for (Taylor & Kvalsvig, 2008). Over one third of households in KwaZulu-Natal live on less than \$2 a day and unemployment is very high (Hoogeveen & Özler, 2006). There is a need to

focus attention on strengthening and supporting families in this type of context (Richter & Desmond, 2008; Richter, 2008). Therefore, it is important to identify issues and challenges faced by families especially those where a child is living with HIV/AIDS in order to inform policies and interventions. This paper reports on a qualitative study that explored how families cared for an HIV-infected child in KwaZulu-Natal.

Methods

Study population

Two groups were targeted for interviews in this study. The first group consisted of 13 women in KwaZulu-Natal who were caring for a child with HIV/AIDS. The second group consisted of 12 professionals in KwaZulu-Natal who had experience working with children and families affected by HIV/AIDS. Purposive sampling was used for each group to select participants with a range of experiences. Several local community-based organizations served as gatekeepers for locating potential participants. To be eligible for the first group, participants had to be mothers who were caring for a biological child under the age of 18 years who was living with HIV/AIDS or a female relative who was entrusted with the care of such a child. Participants in the second group were professionals employed in local NGOs, clinics and hospitals in Durban and Pinetown and they were selected based on their knowledge and experience of working with children with HIV/AIDS and their families.

Procedure

Data collection took place from June 2008 to May 2009. Data were collected by conducting in-depth semi-structured interviews with primary caregivers and key informants. This study was approved by the institutional review boards of the University of KwaZulu-Natal in South Africa and Lehman College in the United States. All interviews were scheduled at a time and place convenient for primary caregivers and key informants and were conducted by trained social workers. Participants in both groups were recruited and interviewed until it was determined that no new themes emerged from the analyses. Semi-structured interviews were conducted with participants from both groups. Interviews typically ran an hour to an hour and a half.

Participants in the first group were asked to describe their experiences of caring for a young child with HIV/AIDS. Participants in the second group were asked to describe their experiences of working with women who were caring for a child with HIV/AIDS. All interviews were conducted by trained Zulu-speaking social workers. All interviews were conducted in isiZulu and recorded. They were transcribed verbatim and translated into English by the interviewers. In acknowledgement of their contribution to the study, participants in the first group were paid R70 (approximately \$10) after completing the interview. Professionals in the second group received no compensation for their participation in this study. Being mindful that the interview process could be stressful or even traumatic for participants (in both study groups), the interviewers solicited feedback from participants about how they were feeling as a result of the interview and referrals to local mental health resources were made when needed.

Data analysis

A thematic analysis was employed in this study. Transcripts of the interviews were carefully read and patterns and themes were identified. Following the coding procedures outlined by Strauss and Corbin (1998), phenomena were grouped into categories of like meaning and the contents of the categories were compared between and within interviews. There was a continuous process of collecting data and comparing data with previously coded data. The qualitative software program NVivo8 was used to mechanically code and facilitate the

analysis of the transcripts of the in-depth interviews. To ensure trustworthiness, coding, themes and key findings were discussed by the research team until consensus was reached.

Findings

The average age of women in the first group was 30. They all had only a few years of primary education and nine of the participants were unemployed. In the second group, two of the participants were male and 10 were female, and their average age was 44. They consisted of counselors, nurses, a social worker and an AIDS project coordinator. They had on average six years professional experience with HIV/AIDS.

Six main themes emerged from the data analysis. Statements illustrating each theme are depicted in Table 1.

Diagnosis

There was a high level of denial in recognizing that a child could be HIV-positive. If the child was very sick, symptoms were often ignored or attributed to other causes. There was a delay in taking the child to the doctor or getting the child tested even when it was known that the woman was HIV-positive. Often it was only when the child was critically ill that a decision was made to get the child tested. In some cases the child was only tested after the mother had died. Finding out the child's status resulted in a mixture of emotions for mothers: relief, fear of dying, worrying about what would happen to the child, and feeling responsible for infecting the child.

Disclosure

The high levels of stigma attached to HIV/AIDS in South African society made disclosing the child's HIV status very difficult. There was concern about the reaction of partners and family members. Women were afraid of being blamed and abandoned. Key informants noted that the failure to get the child tested and lack of disclosure due to stigma caused many children to be treated too late or to not receive proper treatment. A conspiracy of silence surrounding the child's HIV status prevailed in many households. In one instance, one of the women had lost both parents to AIDS as well as an adult sibling, yet she did not feel comfortable telling other family members about her or her child's status. Teachers and principals were usually not informed about the child's HIV status for fear of discrimination. Most children in the study were under ten years of age and had not yet been told that they were HIV-positive because it was felt that they would not understand. The prospect of having to talk to the child about their status was a big cause of anxiety and primary caregivers did not know how they would handle it in the future.

Medical care

Some children had been hospitalized numerous times which took its toll on primary caregivers especially if other family members did not know the child's status or were not available to provide support. After the child recovered, there were fears that the child would not survive the next time. Key informants expressed frustration that some mothers neglected their child's health and were more focused on finding boyfriends and making sure that no-one knew they were HIV-positive as men would not then be interested in them. Men seldom were involved in the rearing of the child let alone participating in their medical care. Visiting the doctor and ensuring that the child took their medications on time as well as getting good nutrition presented a challenge to primary caregivers. They worried about what would happen to the child if they died and they feared that no-one would be willing to assume this huge responsibility.

Not all women were on anti-retroviral treatment (ART) and neither were all the children. Some children were on ART while their mothers were on a waiting list. A common concern was about the side effects of medications and sometimes primary caregivers stopped ART without first consulting the doctor. Other reasons given by primary caregivers for stopping treatment were that the clinic ran out of supplies or the child seemed to be doing well and it was thought that it was no longer necessary. Though there were some instances of hospital and clinic staff being rude or ignoring them, most primary caregivers felt that medical providers were helpful and supportive. Obstacles to medical care included traveling long distances to the clinic or hospital, transport costs, taking time off from work, long waits to be seen, and not having money to buy nutritious food for the child. Key informants were concerned about the state of neglect that many children were in when they were brought in to the clinic or hospital and how widespread beliefs about witchcraft and the use of traditional medicines and advice hampered their ability to effectively treat the child.

Grief

Many primary caregivers had unresolved grief stemming from the loss of other children and family members to AIDS. They constantly worried about their child dying. One woman had lost her parents, her husband, and two children to AIDS and she was bracing herself for the day when her surviving child would die. Despite the high number of deaths in households, there was little discussion of death. Instead the focus was on trying to survive each day, finding money for food, and managing the child's health as well as their own. It was difficult to find time to mourn or to find anyone to talk to about their grief but it was evident in the interviews that thoughts about deceased children and family members were ever present. In the midst of frequent loss, the main challenge was to "keep a positive outlook to life." For family members who had taken over the care of a child who was HIV-positive after the mother had died, the challenge was helping the child cope without their mother and to not feel rejected. It was not uncommon for the father of the child to abandon the child either before or after the death of the mother and often the father had already died.

Poverty

Women with HIV/AIDS in South Africa are typically very poor and depend on one or two family members for shelter and food for themselves and their children. In this study, primary caregivers felt that their future was quite bleak. They focused their energies on living day to day. Finding money to buy food, let alone nutritious food, was a constant preoccupation and source of stress. A common source of income (and often the only source of income) was either a monthly child support grant of approximately \$30 or an old age pension of about \$100. Key informants were highly critical of government's efforts to help children affected by HIV/AIDS and exclaimed that it was impossible to expect families to pay for food, clothing, shelter, and school fees out of these small grants. Primary caregivers sometimes received a food package from a local social service organization in exchange for being a volunteer but many experienced days when there was no food for themselves or their children. Applying for a government grant for a sick child was viewed as more difficult than it needed to be and many people had given up altogether.

Support

Faced with the stress of being HIV-positive, having a sick child, being desperately poor, and in several cases confronted with a violent partner or abusive family members, it was important to find someone who they could count on for support but this proved difficult largely because of the need for secrecy. Most primary caregivers relied on one or two family members for material and emotional support and usually this was far from adequate. Both primary caregivers and key informants expressed frustration with the cultural expectation that women should be solely responsible for caring for a child with HIV/AIDS. Men

provided little financial support for their child and were rarely available or willing to be involved in the physical aspects of caregiving. Most primary caregivers in this study attended church but they did not get much support from their church, usually because they did not disclose their status to members of their congregation or the pastor for fear of being ostracized. While some primary caregivers obtained strength and comfort from their religious beliefs, this was not always the case.

Interest in individual counseling was not widespread. Worrying about basic necessities such as food and money took precedence over seeking help for one's emotions. Key informants said that it was impossible to provide individual counseling to everyone who needed it, let alone those who desired it. Support groups were considered more appealing to both primary caregivers and key informants. Factors that hindered primary caregivers from attending support groups were transport costs, concerns on the part of participants about confidentiality, and needing to focus on other things such as finding a job or getting food. Although key informants understood the need for primary caregivers to prioritize material needs over mental health needs, they expressed frustration over people not keeping appointments or missing group sessions. Support group interventions to help women care for HIV-positive children were considered to work best if there was an income generation component to them or food parcels were provided at each session.

Discussion

Results from this exploratory study in KwaZulu-Natal, South Africa showed that poverty and stigma strongly affected the family's ability to care for a child with HIV/AIDS. Primary caregivers had little income and they had a difficult time applying for government grants. They struggled to buy food for the child and the lack of funds put their child's health in serious jeopardy. Since families play a central role in supporting children affected by HIV/AIDS, more emphasis needs to be placed on reducing poverty and increasing income security as well as improving access to services (Richter & Desmond, 2008; Richter et al., 2009). Households are crippled financially as AIDS impacts the household over a long period of time, from when the child becomes ill until long after their death (Gow & Desmond, 2002). The need for men to be more involved in HIV/AIDS caregiving in South Africa has been widely documented (Orner, 2006; Nysani, Sterberg, & Smith, 2009). Future studies need to explore the role of fathers in strengthening the capacity of families to care for HIV-infected children as well as other children affected by HIV/AIDS and for practitioners and policy makers to increase efforts to engage men more in HIV/AIDS services (Freeman & Nkomo, 2006; Orner et al., 2008).

There is a need to better understand how HIV-related stigma affects the care and treatment of children with HIV/AIDS. Recent studies indicate that high levels of HIV-related stigma are perceived to still exist among communities in South Africa (Visser et al., 2009). We need to aggressively pursue and evaluate strategies that address the complex issue of HIV-related stigma in South African society. Various approaches have been suggested to reduce HIV-related stigma in South Africa including greater commitment at the political level, more support services for people with HIV/AIDS, and public information campaigns showing acts of compassion toward people with HIV/AIDS (Ndinda, Chimbwete, McGrath, Pool, & MDP Group, 2007; Visser et al., 2009). Although it has been suggested that personally knowing someone with HIV/AIDS may reduce stigma (Visser et al., 2009), this is not always the case.

Secrecy due to HIV-related stigma affected primary caregivers' ability to grieve over children previously lost to AIDS and they were unable to share their fears with others about losing another child to AIDS. This is consistent with the findings of a study on AIDS-related

bereavement in KwaZulu-Natal which indicated that stigma played a large role in determining how individuals coped with their loss (Demmer, 2007). Some primary caregivers were reluctant to seek medical treatment for their sick child or to join a support group because they were afraid someone would find out. Greater effort needs to be focused on increasing disclosure among HIV-positive women, building disclosure skills, and helping women assess possible positive outcomes against risks associated with disclosure since non-disclosure can affect infant care and follow up (Varga, Sherman, & Jones, 2005; Visser, et al., 2008).

In this study primary caregivers were doing the best they could under extremely harsh circumstances. Support group interventions have the potential to help mothers and other primary caregivers learn how to cope with and care for a child with HIV/AIDS but it is essential that material needs and emotional needs be addressed simultaneously. Because children and families affected by HIV/AIDS have multiple needs, community initiatives should be comprehensive in nature and not narrowly focused (WHO, 2006). While gains have been made in recent years in making ART more available to children in South Africa, this is another area that needs improvement. Recent estimates indicate that 70,000 children were receiving ART in 2009 out of 106,000 who needed it (Statistics South Africa, 2009). Future studies should explore in more detail the factors that inhibit and promote a family's ability to care for a child with HIV/AIDS and assess the impact of various types of interventions in this area.

Acknowledgments

The project described was supported by Grant Number 1R21NR010423A from the National Institute of Nursing Research from 8/29/2007 to 5/31/2010.

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Table 1

Typical statements by theme.

Diagnosis	Disclosure	Medical care
<p>KI: Many people are still ignorant about HIV signs and symptoms. They rather believe in witchcraft than HIV.</p> <p>PC: We first went to traditional healers because we thought it was some spirits possessing the child.</p> <p>KI: Africans still have a tendency of suspecting everything and anything else when a child is sick, but not HIV.</p> <p>PC: I did not know what was wrong with my child...until one of my neighbors came to me and said "Why don't you take the child to the hospital." That's when I decided to take the child to the hospital.</p> <p>KI: When you give them the child's results, they appear to be more relieved than anything else. It is like they are saying "I am glad this is now out in the open".</p> <p>PC: It is very hard and stressful especially when you know that you have a role in causing that sickness...When she has an illness and feeling sick, I cannot help but feel very sad and guilty that I put my child in this position.</p>	<p>PC: In my community where I stay the HIV story is not well received...</p> <p>PC: One neighbor came to visit and had to witness me taking my medication. She stared at my tablets but never asked or said anything.</p> <p>KI: Once the status of the child is known, mothers fear being evicted by their own families, boyfriends or husbands.</p> <p>PC: There is still so much stigma attached and you can't just disclose to everybody... It's not about me, it's about protecting her, because I wouldn't like people acting nasty to her.</p> <p>PC: I told her about my diagnosis and the child's. She started to act strange, she started to separate dishes, utensils and pots that I was using, she stopped holding my child, she then decided not to enter my room a for fear of infection.</p> <p>KI: Even if you can see that the child has AIDS symptoms, it is still not easy for the mother to just tell you that the child has HIV/AIDS.</p>	<p>KI: Mothers are the ones who deal with the problem from the time when the child is sick to the time when the child dies.</p> <p>KI: They need basic information on caring for a child with AIDS.</p> <p>PC: My main aim is to keep her healthy, to keep her fit, to keep her happy and to make sure that she's taken care of correctly. She's still a child so you have to remind her constantly about things to eat, about what she should drink.</p> <p>KI: I wish you can see some of them when we admit them in hospital. They come so malnourished and unhygienic. They come in a very bad state.</p> <p>KI: Mothers don't disclose their children's status to family members. Then when the child is left with a family member for a day or two, the child is not given treatment. Treatment resistance follows.</p> <p>KI: Most of the children who end up in hospitals are children who did not receive appropriate treatment at clinic level or from their mothers. This happens when the HIV status of the child is not known.</p>
Grief	Poverty	Support
<p>PC: She left a very huge space in my heart (sobbing).</p> <p>PC: It is very hard to watch my child, knowing that she has disease that can kill her... I was already preparing myself for her death.</p> <p>PC: I am worried that my children will be neglected (sobbing). My prayer to God is to live longer to see them growing up and taking care of themselves.</p> <p>KI: They fear that their children are going to die.</p> <p>KI: Each time a child passed on, I always look at all the children who are the same age as the child and start wondering if this child will have a chance to live longer than the dead one.</p> <p>KI: Mothers blame themselves for the death of the child. They need counseling so they can realize that their children's illnesses were not their fault.</p> <p>KI: This child had AIDS symptoms...The child was still depressed about her mother's death...No-one eased her pain of losing a mother or dealing with a dying mother.</p>	<p>KI: People's priorities are to fulfill physiological needs.</p> <p>KI: I think the basic need is food. Yes they need ARV, but also they need food because the child will be having a good appetite.</p> <p>PC: I buy and put it (food) in the fridge. If it is finished, I do not have money then to buy again.</p> <p>KI: There are those who fail to visit their children in hospitals because of financial problems.</p> <p>PC: All I think of is to find a job...Finding employment can make such a difference.</p> <p>KI: When they come here (clinic) we make sure that they get treatment but the challenge of getting food is a bigger one.</p> <p>KI: Grannies and parents are having it tough when it comes to looking after a sick child...They have to respond to so many demands.</p> <p>KI: I think what makes the children die is poverty...Most mothers have no means of support and some are even ill and cannot care for the sick child.</p>	<p>KI: These parents need to acknowledge their pains.</p> <p>PC: Sometimes I would cry alone when things become too hard, and quickly wipe my eyes because I cannot allow my children to see me crying.</p> <p>PC: I would like to hear from them how they are coping with all the challenges associated with being young, being a mother, being HIV, and having two KIDs who are HIV positive with no father's support.</p> <p>KI: The ones that get affected by this stigma end up quitting the support group and isolating themselves at home thus making things worse for themselves.</p> <p>PC: People like to talk about other people's business and I really choose who I talk to.</p> <p>KI: I must tell you that it is a struggle. Clients do not honor appointments or they come once or twice and stop coming but they always come when there are material benefits.</p> <p>KI: People are struggling with serious life issues like food, finances or unemployment. To them, taking care of their emotions is more of a 'want' than a 'need'.</p>

Note: PC: Primary caregiver, KI: Key informant