Published in final edited form as:
Vulnerable Child Youth Stud. 2010 December 1; 5(4): 344–352. doi:10.1080/17450128.2010.516372.

Caring for AIDS-orphaned children: an exploratory study of challenges faced by carers in KwaZulu-Natal, South Africa

Caroline Kuo[a,*] and **Don Operario**[b]

[a]Department of Social Policy and Social Work, Oxford University, Oxford, UK

[b]Department of Community Health, Brown University, Providence, USA

Abstract

Fifteen million children have been orphaned because of AIDS and these numbers are expected to grow in the coming decade. Individuals providing noninstitutional care for AIDS-orphaned children play a critical role in the capacity of communities to respond to the epidemic. However, a limited body of evidence exists on these carers. Studies are urgently needed to build the evidence base on this population, particularly in South Africa which has the largest population of people living with HIV globally. An exploratory qualitative study with carers of AIDS-orphaned children and informants from nongovernmental organizations in KwaZulu-Natal (KZN) province, South Africa, was conducted to (1) explore challenges associated with caring for AIDS-orphaned children and (2) identify areas for more detailed quantitative studies. Findings from this study contribute to a better understanding of AIDS-related impacts on the family by specifically identifying challenges associated with care for AIDS-orphaned children in South Africa.

Keywords

HIV and AIDS; qualitative; care; orphan; South Africa

Introduction

Three decades into the epidemic, we have a growing understanding of how AIDS-related deaths impact families. Studies examine how parental deaths affect well-being, educational and nutritional outcomes of AIDS-orphaned children (e.g. see Cluver & Gardner, 2007; Cluver, Gardner, & Operario, 2007; Ford & Hosegood, 2005). Other studies examine macroeconomic household impacts (e.g. see Bachmann & Booysen, 2003, 2004; Collins & Leibbrandt, 2007). A systematic review of studies on carers of AIDS-orphaned children shows that few studies exist (Kuo & Operario, 2009). This was surprising given that carers support 15 million AIDS-orphaned children (UNAIDS, 2008). Studies suggest that carers face significant impacts from parental deaths and care responsibilities. For example, studies document financial impacts (Freeman & Nkomo, 2006a, 2006b; Heymann, Earle,

*Corresponding author. caroline.kuo@socres.ox.ac.uk.

Rajaraman, Miller, & Bogen, 2007; Jones, 2006; Linsk & Mason, 2004; Miller, Gruskin, Subramanian, Rajaraman, & Heymann, 2006; Safman, 2004), challenges of meeting children's health (Burgos, Hernandez-Reif, Mendoza, Castillo, & Shor-Posner, 2007; Linsk & Mason, 2004) and educational needs (Freeman & Nkomo, 2006a), and carer health issues (Hansell et al., 2002; Joslin & Harrison, 1998; Oburu & Palmerus, 2003). Building additional evidence on this understudied population informs design of evidence-based interventions to support carers.

South Africa is home to 1.4 million AIDS-orphaned children (UNAIDS & WHO, 2008). Yet, few studies have been conducted on carers of AIDS-orphaned children in South Africa (Freeman & Nkomo, 2006a, 2006b; Schroeder & Nichola, 2006; Townsend & Dawes, 2004, 2007). This article reports on findings from a qualitative exploratory study of challenges faced by carers of AIDS-orphaned children in KwaZulu-Natal (KZN) province, the province with the highest prevalence of HIV and AIDS-orphaned children in South Africa (Jacobs, Shung-King, & Smith, 2005). Key study aims included (1) exploring challenges associated with caring for AIDS-orphaned children and (2) identifying areas for more detailed quantitative studies. The study asks, "What are the challenges associated with caring for AIDS-orphaned children in high HIV-prevalent communities in South Africa?"

Methods

Mixed qualitative methods explored challenges faced by adults providing care to AIDS-orphaned children in homes from two perspectives: (1) interviews with respondents at nongovernmental organizations (NGOs) and community-based organizations (CBOs) providing services to carers and/or orphans and (2) focus groups with adult carers responsible for the day-to-day care of AIDS-orphaned children. Data were collected between July and September 2006 from three communities around Durban. Methods were approved by an ethical review committee at Oxford University. Respondents from NGOs/CBOs were identified utilizing a sampling frame of any NGO/CBO that worked with carers or AIDS-orphaned children in KZN. Fourteen staff members were recruited from nine NGOs/CBOs. All respondents were female, spoke English, and 18 years or older. Interviews were conducted in English, recorded and transcribed.

Organizational contacts assisted in recruitment of carers. Carer eligibility criteria included being 18 years or older and providing care to AIDS-orphaned children. Care was defined as looking after a child living in the same household as the respondent. Children were considered orphans if they lost one or both biological parents to AIDS and were not cared for by the remaining biological parent, keeping with policy definitions of orphanhood (UNAIDS, UNICEF, & USAID 2004; UNICEF, 2004). Eighty-four carers participated in two focus groups in the urban community ($n = 8$, $n = 3$), one focus group in the peri-urban community ($n = 37$) and one focus group in the rural community ($n = 36$).[1] Carers were 21–65 years, 9.5% male, 90.5% female, with 98% related to children through kinship and 2% as community members or neighbours. Participants were screened for eligibility and completed informed consent. Discussions were conducted in isiZulu, facilitated by trained research assistants fluent in both isiZulu and English. Sessions were recorded. Research assistants completed field notes in English after each focus group, which were used to direct the transcription and translation of focus group recordings.

Data were analyzed using open coding (i.e. identification and categorization of recurring patterns), axial coding (i.e. reexamination of categories to see how they are linked), and

[1]Peri-urban and rural focus groups were over-attended. Rather than turn-away participants, the research team randomly divided participants into small and more manageable focus groups held concurrently, facilitated by Caroline Kuo and research assistants.

coding of marginal remarks and comparisons (Strauss & Corbin, 1990). This was conducted as an interactive process with research assistants, with data abstracting, coding and categorization for the purpose of identifying thematic content codes. These codes were finalized after transcription.

Results

A major theme emerged around the capacity of extended family to care for children. Respondents noted that HIV had not changed capacity of extended family to take children into their home after parental deaths because historically extended family played a significant role in childcare. For example, an NGO/CBO respondent stated, “even before the epidemic, it has been normal practice for a child to be left with a grandparent while the mother and father work in town” (Respondent A, NGO/CBO 3, 22 August 2006). Similarly, carers confirmed, “many of us already lived in the same house with the parents. When the parents passed, we continued to stay with the children because they were in our house” (Peri-Urban Focus Group, 10 August 2006). Thus, although the epidemic shifted the role of extended family members from that of short-term carers (e.g. while parents were involved in migratory work) to long-term carers, historical patterns of child placement with extended family persist despite high rates of HIV. Although extended family continues to play a key role in childcare, parental deaths increased the responsibility that carers have in children’s lives and presented economic and social challenges.

When respondents were asked to name the top challenges associated with care, three key themes emerged around economic challenges, challenges related to meeting children’s needs, and carers’ health problems (see Table 1). Regarding economic challenges, HIV perpetuated a cycle of poverty and unemployment which was linked to a number of issues including inability to access food, clothing, transport and shelter. In this cycle, parental deaths caused a restructuring of households. Carers described this restructuring stating, “families are now made of many older and younger people and there are a lot more of them in one house” (Urban Focus Group 2, 16 August 2006). Due to this “emerging generation made of the old and young” (Respondent B, NGO/CBO 3, 22 August 2006), “the network of support is becoming smaller both socially and economically because so many relatives die” (NGO/CBO 7, 25 August 2006). Thus, parental deaths resulted in household economic shocks that generated a cycle of poverty. One story in particular highlights this cycle:

> This particular mom is an example of how the epidemic has contributed to poverty. This mother cannot go to work because she has to look after… a large number of kids who are orphaned as well as her own. The epidemic reinforces this cycle of poverty. If the people in the valley do find work, the eldest children typically look after children. However, this creates problems because they are deprived of proper schooling. (Respondent B, NGO/CBO 3, 22 August 2006)

Thus, parental deaths were linked to household changes that may have exacerbated financial challenges carers face.

Another key mechanism contributing to economic challenges were administrative and eligibility barriers in the state-supported social grants system. All focus groups and NGO/CBO respondents recognized state-supported grants as “a lifeline for caregivers” (NGO/CBO 7, 25 August 2006). However, documentation requirements prevented some carers from accessing child support grants (230ZAR or approximately 22USD per month) despite meeting other eligibility requirements:

> It is problematic to get birth and death certificates … To get documentation, you have to go back and find relatives of the parents, but the father has never been identified. So you have to get the mother’s relatives to go swear affidavits at a

> certain place which you then have to bring into the magistrate's office. (NGO/CBO 9, 1 August 2006)

In addition, respondents suggested that the 14-year age limit for the child support grant excluded older children who needed the grant; South Africa recently raised the age limit to 18 years, thus addressing these concerns. Another issue related to poverty was that ownership of children's documentation had become a source of family conflict:

> When family members die, some families do not care about the children but do care about the certificates because this is a source of income. The family members negotiate who gets the certificate. (Respondent A, NGO/CBO 8)

This example shows that individuals pursuing grants were not necessarily doing so to gain funds for children. In terms of the foster care grant (650ZAR or approximately 62USD per month), respondents suggested that the application process needed to be reexamined given that "it used to be for children who needed to be removed for safety. It is now being used to accommodate orphans," particularly in kin-headed households (Respondent B, NGO/CBO 1, 7 August 2006). This suggests that in the context of AIDS, the foster care grant is being used for purposes different from its original intent – to support adults caring for children removed from their home because of risk for violence, abuse and so on. The eligibility criteria for the grant may have been appropriate for its original purposes, but in the context of caring for AIDS-orphaned children, use of this grant may need to be reconsidered. In sum, carers confronted a number of economic challenges.

In addition to economic challenges, challenges relating to meeting children's needs also emerged as a major theme. Respondents highlighted how parental deaths created challenges related to meeting children's needs. Carers argued that parental deaths resulted in the absence of adult family members who played important roles in child socialisation. Carers described the impact of deaths on the child-rearing process, stating it was "hard to provide guidance to our children because many family members have died from AIDS" (Peri-Urban Focus Group, 10 August 2006). Moreover, respondents described that carers had difficulty in meeting children's emotional needs (e.g. attention and love) as well as addressing bereavement:

> [Carers are]… concerned about physical well-being. Some are concerned about education. Some of the grandmothers have spoken about their sense of the need to address emotional and social issues, but say that they struggle with this aspect. (Respondent A, NGO/CBO 4, 25 July 2006)

Carers faced difficulties in meeting needs because of competing priorities. For example, NGO/CBO respondents felt carers were "concerned with the most basic needs – primarily food, clothes, shelter which is not large enough for these growing families of children left behind, and some love *if there is time*" (emphasis added, Respondent B, NGO/CBO 3, 22 August 2006).

In addition to facing difficulties in meeting children's needs, carers faced health issues. Physical illness posed challenges for childcare but also was a concern because "many people [were] worried that when they pass away, there will be no one to care for the child" (Peri-Urban Focus Group, 10 August 2006). Carers also described mental health needs such as high stress. Stress was linked to challenges of disciplining children with carers saying, "those who stay with children have trouble with them sometimes. These children act naughty sometimes. This can be a problem" (Rural Focus Group, 17 August 2006). NGO/CBO respondents confirmed this saying, "Caregivers are having trouble with discipline. The children sometimes become very rebellious against their grandmothers" (NGO/CBO 2, 14 August 2006). Carers also struggled with bereavement. A NGO/CBO respondent pointed out

that childcare was made even more difficult because, "the grandmother is old and she has lost a child so she also has her own emotional issues to deal with" (NGO/CBO 2, 14 August 2006). Finally, carers struggled with AIDS stigma saying, "a huge problem is discrimination" (Rural Focus Group, 17 August 2006). Stigma resulted in isolation of carers and children from social networks. Carers described isolation stating, "Many people are afraid to keep in touch with family because of HIV/AIDS in many ways" (Rural Focus Group, 17 August 2006). In sum, health emerged as a key challenge.

Although results highlighted difficulties experienced by carers, it should not be assumed that all carers faced the same challenges. For example, even though economic hardships emerged as an important challenge, an NGO/CBO respondent suggested that elderly carers experienced a higher degree of economic hardship:

> Elderly women face special challenges … they want to care for the children to the best of their ability. However they cannot because they are not getting anything. It is more difficult to extend their help to these children because they do not have anything. (Respondent A, NGO/CBO 3, 18 August 2006)

Similarly, carers stated,

> Grandparents are over sixty [years of age] and cannot find employment … Many older people depend on disability funds or [old age] pension funds which is not a lot to take care of a family that is sometimes more than ten people. (Urban Focus Group 2, 16 August 2006)

NGO/CBO respondents also argued that aunt carers faced difficulties combining children into an existing family dynamic. One respondent said:

> Maybe you have four children of your own and four more are coming to join your family; it is a huge challenge to combine these children and treat them as your own. (Respondent B, NGO/CBO 4, 25 July 2006)

Quality of care may have differed according to capacities of kin carers.

> The children being cared for by grannies are doing far better than the children being cared for by aunties. The grannies are nurturing and have special love for the children … The aunties don't have time and have their own issues maybe with husbands, other children. (Respondent C, NGO/CBO 4, 25 July 2006)

These data suggest that different types of carers may have unique needs as well as varying challenges and capacities for childcare which are related to their age and relationship to the child.

Discussion

This study explored challenges carers confronted in high HIV-prevalence communities. Respondent narratives suggested that AIDS-related parental deaths have not caused a crisis in child placement because historically primary childcarers have been nonparental figures. This finding is confirmed by other literature. For example, Madhavan argues that children have historically been "fostered by a variety of kin and, sometimes, non-kin. Therefore, child fostering has always been and continues to be a crucial part of black family life" (2004, p. 1443). Cock et al.'s national study of urban South African childcare shows that "almost 40 percent of women left children with adult relatives, particularly grandmothers, and 10 percent left their children with older siblings" (1986, p. 81). Giese et al.'s (2003) study also confirms "the characteristically nonnuclear nature of South African household relationships" in which "children remain in their homes upon the death of their parent(s), with a continuum of care provided by other adults with whom they are resident at the time"

(cited in Meintjes and Giese, 2006, p. 412). Although the broader literature confirms that extended families play an important role in care, other data highlight a high level of strain felt by carers.

The challenges carers faced drew attention to how the sheer volume of parental deaths contributed to household economic shocks, increasing poverty, and unemployment. Findings also highlighted how current administration of state-supported grants exacerbated economic challenges. Particularly concerning was that documentation for grants was a source of family conflict in which children's best interests may remain unmet. This suggests that policies must focus on ways of verifying that grant recipients implement funds for childcare. Parental deaths also impacted availability of social support, resulting in challenges related to childcare, including socialization and emotional needs. Finally, carers faced health issues related to care. Significantly, respondents drew attention to the differential needs, motivations, abilities and challenges faced by varying types of kin carers.

This exploratory study identified several areas for future research. First, there is the need to identify and quantify extent of care challenges in high HIV-prevalent communities. Related to this is the need to identify who is caring for children and to quantify how challenges vary according to carer type (e.g. kin vs. non-kin, different types of kin carers). A second area for future research includes the need to investigate carer well-being; the systematic review showed that few studies directly investigated the health of those caring for AIDS-orphaned children (Kuo & Operario, 2009) but health emerged as a significant challenge in this study. Such investigations are needed to understand how care challenges and patterns of care placement impact upon carer well-being. Third, more studies need to identify factors mediating carer well-being. Fourth, longitudinal studies are needed to determine whether differences in child outcomes arise because of changing care circumstances including, for example, parental illness, parental death and placement into a new care situation.

There are important limitations of this study. First, findings are context specific because this study focused solely on communities within the Durban area, and recruitment techniques could not guarantee that all substantial subgroups of the population were included. Second, this study would have benefited from additional in-depth interviews with carers to explore how they overcome these challenges. Third, although this study allowed one to explore challenges associated with the care experience, sampling methods and sample size preclude statistical inferences about the prevalence of social or economic challenges because of lack of a representative sample.

Clear implications follow from this study. Findings suggest that interventions directed at families need to take into account the abilities, needs and challenges faced by different types of carers, rather than assume that they are the same for all carers. Interventions designed to address structural factors such as administration of the state grants system may improve outcomes for both carers and children. The types of risk and protective factors associated with care challenges need to be validated through representative sampling and interventions need to be evaluated and monitored to assure that improvements are achieved and sustained.

Acknowledgments

This research was supported by Award Number F31MH081820 from the National Institute of Mental Health to Caroline Kuo. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institute of Mental Health or the National Institutes of Health. This research was also supported in part by the Leverhulme Trust Grant F08-599C to Don Operario.

References

Bachmann M, Booysen F. Health and economic impacts of HIV/AIDS on South African households: A cohort study. BMC Public Health 2003;1(3):14. [PubMed: 12667263]

Bachmann M, Booysen F. Relationships between HIV/AIDS, income and expenditure over time in deprive South African households. AIDS Care 2004;16(7):817–826. [PubMed: 15385236]

Burgos N, Hernandez-Reif M, Mendoza R, Castillo R, Shor-Posner G. Caregivers' perception of HIV-infected Dominican children's behaviour. West Indian Medical Journal 2007;56(1):42–47. [PubMed: 17621843]

Cock, J.; Emdon, E.; Klugman, B. The care of the Apartheid child: An urban African study. In: Burman, S.; Reynolds, P., editors. Growing up in a divided society: The contexts of childhood in South Africa. Johannesburg: Ravan Press; 1986. p. 66-92.

Cluver L, Gardner F. The mental health of children orphaned by AIDS: A review of international and South African research. Journal of Child and Adolescent Mental Health 2007;19(1):1–17.

Cluver L, Gardner F, Operario D. Psychological distress amongst AIDS-orphaned children in urban South Africa. Journal of Child Psychiatry and Psychology and Allied Disciplines 2007;48(8):755–763.

Collins D, Leibbrandt M. The financial impact of HIV/AIDS on poor households in South Africa. AIDS 2007;21 Suppl. 7:S75–S81. [PubMed: 18040168]

Ford K, Hosegood V. AIDS mortality and the mobility of children in KwaZulu Natal, South Africa. Demography 2005;42(4):757–768. [PubMed: 16463920]

Freeman M, Nkomo N. Assistance needed for the integration of orphaned and vulnerable children – views of South African family and community members. Journal of Social Aspects of HIV/AIDS Research Alliance 2006a;3(3):503–509. [PubMed: 17601337]

Freeman M, Nkomo N. Guardianship of orphans and vulnerable children. A survey of current and prospective South African caregivers. AIDS Care 2006b;18(4):302–310. [PubMed: 16809107]

Giese, S.; Meintjes, H.; Croke, R.; Chamberlain, R. Health and social services to address the needs of orphans and other vulnerable children in the context of HIV/AIDS in South Africa: Research report and recommendations. Cape Town, South Africa: University of Cape Town; 2003.

Hansell, P.; Hughes, C.; Caliandro, G.; Russo, P.; Budin, W.; Hartman, B.; Hernandez, O. Stress and social support in older caregivers of children with HIV/AIDS: An intervention model. In: Joslin, D., editor. Invisible caregivers: Older adults raising children in the wake of HIV/AIDS. New York: Columbia University Press; 2002. p. 113-130.

Heymann J, Earle A, Rajaraman D, Miller C, Bogen K. Extended family caring for children orphaned by AIDS: Balancing essential work and caregiving in a high HIV prevalence nations. AIDS Care 2007;19(3):337–345. [PubMed: 17453567]

Jacobs, M.; Shung-King, M.; Smith, C. South African child gauge. Cape Town: Children's Institute, University of Cape Town; 2005.

Jones L. Childcare in poor urban settlements in Swaziland in an era of HIV/AIDS. African Journal of AIDS Research 2006;4(3):161–171.

Joslin D, Harrison R. The "hidden patient": Older relatives raising children orphaned by AIDS. Journal of the American Medical Women's Association 1998;53(2):65–71.

Kuo C, Operario D. Caring for AIDS-Orphaned children: A systematic review of studies on caregivers. Vulnerable Children and Youth Studies 2009;4(1):1–12.

Linsk N, Mason S. Stresses on grandparents and other relatives caring for children affected by HIV/AIDS. Health and Social Work 2004;29(3):127–136. [PubMed: 15156845]

Madhavan S. Fosterage patterns in the age of AIDS: Continuity and change. Social Science and Medicine 2004;58(7):1443–1454. [PubMed: 14759688]

Meinjtes H, Giese S. Spinning the epidemic: The making of mythologies of orphanhood in the context of AIDS. Childhood 2006;13(3):407–430.

Miller C, Gruskin S, Subramanian S, Rajaraman D, Heymann J. Orphan care in Botswana's working households: Growing responsibilities in the absence of adequate support. American Journal of Public Health 2006;96(8):1429–1435. [PubMed: 16809585]

Oburu PO, Palmerus K. Parenting stress and self-reported discipline strategies of Kenyan caregiving grandmothers. International Journal of Behavioral Development 2003;27(6):505–512.

Safman R. Assessing the impact of orphanhood on Thai children affected by AIDS and their caregivers. AIDS Care 2004;16(1):11–19. [PubMed: 14660140]

Schroeder E-A, Nichola T. The adoption of HIV/AIDS orphans and food security in rural Ingwavuma, South Africa. International Journal of Technology Management & Sustainable Development 2006;5(2):173–187.

Strauss, A.; Corbin, J. Basics of qualitative research: Grounded theory procedures and techniques. London: Sage Publications; 1990.

Townsend L, Dawes A. Willingness to care for children orphaned by HIV/AIDS: A study of foster and adoptive parents. African Journal of AIDS Research 2004;3(1):69–80.

Townsend L, Dawes A. Intentions to care for children orphaned by HIV/AIDS: A test of the theory of planned behavior. Journal of Applied Social Psychology 2007;37(4):822–843.

UNAIDS. 2008 Report on the Global AIDS Epidemic. Geneva: UNAIDS; 2008. Document Number

UNAIDS & WHO. UNAIDS/WHO epidemiological fact sheets on HIV and AIDS, 2008 Update. 2008.

UNAIDS, UNICEF, & USAID. Children on the brink 2004: A joint report of new orphan estimates and a framework for action. New York: USAID; 2004. Retrieved from http://apps.who.int/globalatlas/predefinedReports/EFS2008/full/EFS2008_ZA.pdf

UNICEF. The framework for the protection, care and support of orphans and vulnerable children living in a world with HIV and AIDS. New York: United Nations Children's Fund; 2004. Retrieved from http://www.unicef.org/aids/files/Framework_English.pdf

Table 1

Frequency of responses to challenges associated with caring for AIDS-orphaned children.

Challenges related to care provision	NGO/CBO respondents (*n* = 14) (number of respondents who commented on topic)	Carer respondents (*n* = 84) (number of times these topics were commented on by any carer)
Economic challenges		
Poverty	8	9
Food	5	9
Accessing documents for social welfare grants	4	5
Shelter	4	10
Unemployment	3	3
Clothing	3	7
Transport	2	4
Clean water	0	3
School fees/uniforms	9	11
Challenges related to children's needs		
Sexual abuse of children	2	1
Disciplining children	2	1
Children's emotional needs	1	1
Children's bereavement	1	0
Children's physical health	2	1
Physical and mental health challenges		
Carer bereavement	2	1
Disappointment about unmet expectations regarding life course	1	0
Tiredness and stress due to caring for children	4	0
Stigma	6	1
Carer's sense of isolation	1	0
Stress of combining families	1	0
Carer physical health	2	1

Note: This table denotes the frequency of responses when NGO/CBO respondents and carers were asked to name the top challenges associated with care.