



Sociocultural Issues as Barriers to HIV-Infected Orphan Care in Southern Africa

Seth Langsam¹, Corinne Lehmann^{2,3*}, Lisa M. Vaughn^{2,4,5}, Alexandra Kissling^{4,6}

1. University of Cincinnati, College of Medicine
2. University of Cincinnati, College of Medicine, Department of Pediatrics
3. Cincinnati Children's Hospital Medical Center, Division of Adolescent Medicine
4. Cincinnati Children's Hospital Medical Center, Division of Emergency Medicine
5. University of Cincinnati, College of Education, Criminal Justice, and Human Services, Division of Educational Studies
6. University of Cincinnati, College of Arts & Sciences, Department of Sociology

Abstract

As advances in treatment and prevention are starting to decrease the magnitude of the Acquired Immunodeficiency Syndrome (AIDS) epidemic in Sub-Saharan Africa, the number of orphans and children surviving Human Immunodeficiency Virus (HIV) infection is growing. To date, little research has been conducted in the care of HIV-infected children in orphanages in Sub-Saharan Africa. In this qualitative study, managing personnel in 10 programs caring for HIV-infected children were interviewed to ascertain perceived barriers to care of these children. While all programs commented on medical infrastructure barriers, respondents felt sociocultural issues were more pressing. After analysis of transcribed interviews, three major themes of poverty, denial/stigma, and cultural differences with outsiders emerged. These findings have implications for international programs that both serve and seek to serve the needs of HIV-infected children and orphans in Africa. Outside funding organizations will need to address local poverty, stigma, and African "ownership" of HIV-positive orphans to ultimately ensure the best care of these vulnerable children.

Key Words: Orphans and vulnerable children, Human Immunodeficiency Virus, Acquired Immune Deficiency, poverty, stigma, cultural differences, South Africa, Sub-Saharan Africa, Swaziland

Corresponding Author:

Corinne Lehmann, M.D., M.Ed.
3333 Burnet Avenue, ML 4000, Cincinnati, OH 45229,
Phone: 513-636-8591, Fax: 513-636-1129, corinne.lehmann@cchmc.org

Received: March 05, 2013; **Accepted** : April 30, 2014; **Published:** June 09, 2014;

Introduction

"No child should be born with HIV; no child should be an orphan because of HIV; no child should die due to lack of access to treatment," urged Ebube Sylvia Taylor, an 11-year-old born free of HIV, to world leaders gathered in New York to share news of the progress made toward achieving the Millennium Development Goals by 2015 [1].

Sub-Saharan Africa has been unequally affected by the global AIDS epidemic. While the number of new HIV infections in adults decreased by 34% from 2001-2012, the number of adults living with HIV infection in Sub-Saharan Africa has increased due to expanded treatment programs [1]. Of the 23 million HIV-infected adults and children living in Africa in 2011, 5.1 million adults were located in South Africa alone [2]. In addition, efforts to prevent maternal-to-child transmission of HIV through expanded access to HIV treatment have led to a global decrease of new infections in children. However, as with adults, the number of children living with HIV has also increased worldwide from 1.8 million in 2001 to 3.3 million in 2011, when an estimated 460,000 HIV-infected children were living in South Africa [2].

Orphanhood is commonplace for HIV-infected children in Sub-Saharan Africa. The plight of orphans and vulnerable children (OVCs) in Africa has become the subject of much attention over the last several years, highlighted by the involvement of numerous international organizations and governments as well as celebrities. According to the Joint United Nations Programme on HIV/AIDS (UNAIDS) Global Report in 2010, "Despite the modest decline in HIV adult prevalence worldwide and increasing access to treatment, the total number of children aged 0-17 years who have lost their parents due to HIV has not yet declined. Indeed, it has further increased from 14.6 million (12.4 million–17.1 million) in 2005 to 16.6 million (14.4 million–18.8 million) in 2009. Almost 90% live in sub-Saharan Africa [1]." In 2012, the United States

President's Emergency Plan for AIDS Relief (PEPFAR) estimated that their program served 516,400 OVCs in South Africa and 89,400 OVCs in Swaziland [3].

As the number of OVCs continues to increase, numerous governments and other organizations have attempted to intercede in caring for orphans by using residential-type programs. OVCs in Africa are typically taken in by extended family members. In a study conducted in Zimbabwe, nearly 90% of adults surveyed stated they would be willing to take in an orphaned child, with family financial ability and degree of kinship presenting as the most important factors in the decision [4]. Although several studies have focused on barriers to orphan care within a family context, few studies exist on barriers to institutional or residential care of African orphans, let alone HIV-infected orphans. This study seeks to explore the barriers to care for HIV-infected orphans within an institutional- or residential care-type system in South Africa and Swaziland. Even as substantial inroads are being made to decrease the rates of HIV infection and transmission in adults, poor care of HIV-infected orphans could serve to perpetuate HIV transmission in Africa. We hypothesize that infrastructure issues surrounding funding, transportation, and medical supply delivery would be the most difficult elements of care to coordinate for HIV-infected orphans.

Experimental Procedure

This study comprised a qualitative analysis of interviews conducted with managing personnel of various institutions that care for HIV-infected orphans. Semi-structured interviews were conducted once at each institution over the course of a five-week period during June and July 2007 by the principal investigator, who asked questions from an interview guide previously written by the study investigators. Each interview was digitally audio-recorded and transcribed verbatim. The

(Continued on page 29)

transcripts and interviewer notes were reviewed by the research team so as to familiarize themselves with the data and content.

Using a standard qualitative research procedure based on the grounded theory approach to qualitative data analysis [5,6], three members of the research team independently reviewed the transcripts through multiple readings and subsequently coded the phrases, thoughts, and meanings of the participant's words as they related to the care of HIV-positive orphans living in orphanages. After multiple discussions involving each team member's results from the coding sessions, the research team identified broad conceptual categories and salient themes rather than imposing preconceived categories or models. This process of data analysis allowed the themes to evolve inductively, thereby reflecting "the ground" (i.e., the experience of the participants). Final salient themes were verified among the research team for clarification, consensus, and validation. This study was approved by the Institutional Review Board (IRB) of the University of Cincinnati, Cincinnati, Ohio.

Materials and Methods

Eligibility for interview participation included any institution or residential care facility that was directly responsible for care of any HIV-infected orphans, and recruitment occurred through email, telephone, and referrals by HIV-related and health care organizations in South Africa and Swaziland. Of the 17 organizations identified and approached to participate, 10 signed a consent form; seven chose not to participate, with three programs cancelling interviews and four stating they could not participate without the approval of their local IRB.

Ten organizations were recruited from South Africa and Swaziland, including the Western Cape, Pretoria, Johannesburg, and the Kwazulu-Natal Province in South Africa along with Mbabane in Swaziland. Participants included five orphanages that cared for HIV-

infected children and five institutions providing other types of care programs for HIV-infected orphans. Of the five latter institutions, three were "mother-run" houses that incorporated both regular medical care and hospice care for HIV-infected orphans, one was a hospice and home-based program, and one was a comprehensive HIV community outreach program that also included a hospice program.

Results

Although all participating organizations commented on various specifics of health care delivery to pediatric HIV-infected patients, the vast majority of responses focused on sociocultural barriers to the care of HIV-infected orphans. Using the qualitative data analysis approach described above, three salient sociocultural themes emerged from the interviews: (1) poverty, (2) denial/stigma, and (3) cultural differences with outsiders.

Poverty

Poverty in the local communities, both in terms of limited resources available to providers and at the individual family level, was cited by every organization as a barrier to care—one that affects all levels of society's response to the plight of orphans and pediatric HIV patients. Respondents noted that poverty affects how their national and local governments, as well as the local community, coordinate the delivery of medical care to orphans and manage the overload of welfare systems. One respondent noted that "*caring for HIV-positive individuals takes both time and money; living in extreme poverty like a lot of our country is doing makes meeting these two demands almost nearly impossible.*"

Poverty affected the care options available to participating organizations. Although eight organizations had contact with a government-run facility, a common sentiment was that these facilities offered substandard care: "*The care given at the local government hospital is not good enough for our children*" However,

respondents explained that the advantage of accessing these facilities is their comparatively reduced cost of medical care. Swaziland participants noted that the pediatric HIV program of an international academic medical center program offered free high-quality care for pediatric HIV-infected patients. However, the downside of this system of care is its dependency on foreign funding and foreign providers. Almost all of the respondents stated that seeking medical care at private clinics was an option not often utilized. Even though private clinics were viewed as offering more extensive care of adequate quality than government-run facilities, they were considered too expensive and typically beyond the affordability of most local populations and organizations.

Six respondents expressed the view that poverty leads to an inundated social welfare system in Southern Africa. Due to a high number of caseloads along with the additional social and medical issues surrounding HIV-infected orphans, some respondents stated that social workers were more likely to place HIV-positive children in an institution rather than in the community: "... *It is often more successful to put a child in a children's home where they pay for privately sponsored treatment rather than trying to treat an orphan in a community-based program*". *"If the child is placed here with us, the (social workers) are so relieved that the child is placed they just go on with the other 200 crises..."* Respondents noted that there are not enough social workers to address the serious needs associated with HIV-infected orphans. Not placing children within the community was perceived by respondents as a transfer of the responsibility of care away from the local community, resulting in children being raised by outsiders/foreigners: "... *We want to adopt within Swaziland more than people from outside coming in wanting to take children because Swazi's need to be raised by Swazi's. That is the culture.*" Respondents felt that not following the cultural traditions

embedded within the local communities would ultimately produce negative outcomes for HIV-infected orphans.

Denial/Stigma

Respondents discussed the following four related issues surrounding denial and the stigma associated with HIV-positive orphans, all of which diminish treatment opportunities: (1) men and denial of HIV, (2) decreased rates of disclosure and potential care, (3) social isolation, and (4) fatalism regarding HIV diagnosis.

Men in both South Africa and Swaziland were particularly singled out by three organizations as being in denial about the prevalence of HIV and AIDS in general. Respondents stated, *"When a child dies and is HIV positive, the mother says please don't tell the father because he doesn't know he's [the child's] HIV positive. That's part of the culture ... the men will either leave or abuse her if he knows she is positive ... it's quite a problem."* Because of the stigma associated with HIV, respondents said that male heads of households who maintain a dominant status in the community might influence whether HIV testing occurs at all, both in the immediate family and within the larger community.

The fact that the stigma of HIV leads to decreased rates of disclosure and thus to decreased access to potential care was noted by three programs: *"They (parents) don't want to get treatment for the children because people will know they are positive I think this is a big barrier. That is the reason why often these children are neglected at home because they don't want people to know ... so they don't come and look for help."* Even directors of organizations known to care for HIV-positive children said that they keep the HIV status of orphans fairly hidden and advise orphans not to disclose this information due to the shame and stigma associated with this status in the community.

Three respondents explained that HIV-positive orphans might be subjected to social isolation and that

this isolation would result in a lessened likelihood of receiving treatment: *"If the people in the community know, they may shun these children ... I mean, they are not in a secure home before they become HIV-positive, then they are even in less of a secure home afterwards. They are more likely to be abandoned than they were before."*

Three respondents reported a fatalistic attitude in the government regarding the overwhelming number of HIV diagnoses and an associated diffusion of responsibility for the care of HIV-infected orphans: *"... One sits and wonders if the government hasn't done it on purpose because what were they going to do with all these orphans anyway. So, hey, let a few of them die and then we'll carry on from there."*

Cultural Differences with Outsiders

Most comments about perceived cultural differences with outsiders regarding HIV infection and orphan care involved purported differences between Africans and non-Africans. Half of the respondents described the challenges of providing appropriate sex education for their HIV-infected orphans while concurrently staying within the guidelines dictated by the funding program administration. Of the three religiously funded institutions in this study, two offered abstinence-only-based sexual education, and one program (self-identified as Christian) said they did not offer sex education at all due to the age range of the children. The other participant programs generally offered combination approaches to sex education, with the core theme of the approach still centering on abstinence. Nevertheless, some program respondents described the reality of their situation as follows: *"Obviously we spend a lot of time talking about HIV/AIDS and sex ... because of our religious affiliation, we highly stress abstinence; however, as realists, we know that we also need to teach about safe sex practices, and we spend a large amount of time teaching all about the HIV/AIDS virus, including transmission"*

Half of the programs cited lack of HIV knowledge and prevalent misconceptions in the general population as barriers to care for HIV-infected children. Respondents also did not like the idea of outsiders delivering HIV information, even if the information was accurate. For instance, a non-African working in one of the programs commented that *"... (education) has to come from somebody in their community that they trust, that they can relate to, and who can explain it to them in a way that is nonthreatening. Coming from a white person who is not totally familiar with the culture and probably never will be ... it does no good for us to go and try to counsel. It has to come from somebody they trust."*

Two program respondents commented on the cultural differences between an international funding source and local programming: *"... If someone comes with money, they will want things done their way. He who pays the piper, plays the tune"* Respondents noted that there is a strong pull to keep children absorbed in some sort of traditional African family unit so as to preserve local culture and that international adoption of HIV-infected orphans is not viewed as benefiting the child or the community.

Discussion

The purpose of this study was to examine perceived barriers to care of HIV-infected orphans from the perspective of 10 programs caring for these orphans in South Africa and Swaziland. While all programs commented on medical infrastructure barriers, respondents felt sociocultural issues were more pressing. Three major sociocultural themes of poverty, denial/stigma, and cultural differences with outsiders emerged from these qualitative interviews. While literature surrounding the issues faced by OVCs in South Africa is growing, most focuses on family or foster care of these children within their community. This study adds to the literature regarding those HIV-infected

children who have been placed into a care institution or orphanage.

In several studies, poverty has been cited as a barrier to care for orphans affected by the death of their parents from HIV/AIDS. This poverty can be interpreted on a personal level when families do not have enough money to access appropriate HIV care [7] or when the HIV-related illness of a parent leads to increased poverty [8]. Poverty can also be considered on a regional or national level as a barrier to care for HIV-infected orphans. Yet, many countries in Africa have made progress in assuming a greater financial role in funding their responses to HIV care. For example, South Africa now covers more than 75% of their national HIV responses through domestic public sources [9]. However, HIV-infected children receive treatment at about half of current adult treatment levels. The scale-up of antiretroviral treatment programs in children have lagged behind those of adults in general [9]. As cited by our respondents, more affordable and effective treatment programs are needed to treat HIV-infected orphans.

The denial and stigma of HIV play into yet another barrier to care for orphans with HIV infection. HIV-related stigma can lead to poor engagement with HIV care services [10]. Some participants revealed a sentiment of fatalism in their communities that some HIV-infected orphans would never be treated. In a study of community-dwelling adolescents in South Africa, just over half of the participants had disclosed their HIV-positive status beyond their immediate care-giving family [7]. While our respondents were generally able to seek care for their HIV-infected orphans, most institutions chose to keep the HIV status of these children secret so they would not be shunned by the local community. As these adolescent HIV-infected orphans mature and leave their care institutions, focused attention must be directed toward how they

manage to access HIV care and services on their own if the stigma of HIV persists in their country.

As African countries strive to take financial ownership of the effects of the HIV epidemic, our respondents also indicated that there are other levels of care that governments must also address. In a 2006 study of 1400 adults in South Africa, 76% identified a family-related guardian who would care for their biologic children if they were no longer able to care for them. Approximately 10% of the study participants answered "the government," "other," or "I don't know" when asked this question [11]. Our institutional respondents also acknowledged this societal expectation of extended families to take in HIV-infected orphans. Continued growth of the HIV/AIDS orphaned population in sub-Saharan Africa could possibly increase the demands on institutional care when extended families cannot care for their biologic relatives. Institutions that do not respond to the local culture may serve to weaken the community's coping mechanisms in dealing with orphans [12]. It remains to be seen whether HIV-infected orphans in the care of foreign-run institutions will be further stigmatized as not being an integral part of their community or cultural tradition.

Lack of HIV education was also noted by several institutions as an ongoing issue with their HIV-infected orphans. In a 2006 study of both clinic staff and patient caregivers at six private community-based clinics in South Africa, participants cited the need for accurate HIV information to be disseminated by health care workers, the media, and the government. "*Many participants felt that better HIV knowledge was needed among the general public to increase care-seeking for children and to reduce stigma...*" [13]. Our respondents echoed this sentiment, with one highlighting a pervasive distrust of foreigners in delivering HIV education. Of further concern, many surveyed institutions reported using an abstinence-based method of sexual education and instruction for the prevention of HIV transmission,

with mandates to use abstinence-based methods issued by some foreign funding sources. Comprehensive sexual education methods that include instruction on condom use have shown efficacy in delaying sexual debut and increasing the use of condoms [14], whereas abstinence-based methods have not. It is crucial that this generation of HIV-infected children receive appropriate HIV information from trusted sources so as to avoid perpetuating the transmission of HIV themselves.

One limitation of this qualitative study involving barriers to obtaining care for HIV-infected orphans in South Africa and Swaziland is that the data may not be generalizable to other populations in other settings or countries. Our cohort was a convenience sample of organizations in a relative geographic area that were willing to participate. Our inability to secure IRB approval from local institutions limited the recruitment of additional institutions into the study. Moreover, the institutions surveyed were a mix of "mother-run houses" where children lived on-site and of "care points" where children may still live with extended family or other community members while accessing a centralized location for medical care, nutrition, and schooling. This mixture of program styles may be regarded as a strength of the study because it ostensibly introduces various points of view and is representative of different care paradigms available to orphaned HIV-infected children in Sub-Saharan Africa. Although our structured survey questions may have precluded further questioning about potential sociocultural barriers, we found that managing personnel from the surveyed institutions provided rich responses to our open-ended questions and mirrored the findings of other community-based programs that care for orphans in South Africa.

Conclusions

While the number of new pediatric HIV infections in sub-Saharan Africa may truly be waning, the number of children orphaned by HIV/AIDS continues to escalate. For those HIV-infected orphans who are

placed in an institution, poverty, stigma, and cultural differences present barriers to their care. Future international endeavors related to the care of OVCs in orphanage-style settings in sub-Saharan Africa will need to focus their attention and resources on the pervasive issues of poverty, stigma, and local cultural attitudes in raising children so as to provide comprehensive care for these children.

Acknowledgements

The authors would like to thank Jan Clavey, BA, in the editing, preparation, and submission of this manuscript.

Conflicts of Interest

The authors have no conflicts of interest to report.

References

1. Joint United Nations Programme on HIV/AIDS. UNAIDS report on the global AIDS epidemic 2010. http://www.unaids.org/globalreport/global_report.htm. 2010. Accessed October 18, 2013.
2. World Health Organization. Global health observatory data repository. 2013. <http://apps.who.int/gho/data/node.main.617?lang=en>. Accessed October 18, 2013.
3. United States Presidents Emergency Plan for AIDS Relief (PEPFAR). Ninth annual report to Congress. <http://www.pepfar.gov/press/207539.htm>. 2013. Accessed October 18, 2013.
4. Howard BH, Phillips CV, Matinhure N, et al. Barriers and incentives to orphan care in a time of AIDS and economic crisis: a cross-sectional survey of caregivers in rural Zimbabwe. *BMC Public Health* 2006;6(1):27.

5. Glaser B, Strauss A. *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Hawthorne, NY: Aldine de Gruyter; 1967.
6. Crabtree B, Miller W. *Doing Qualitative Research*. 2nd ed. Thousand Oaks, CA: Sage Publications; 1999.
7. Peterson I, Bhana A, Myeza N, et al. Psychosocial challenges and protective influences for socio-emotional coping of HIV+ adolescents in South Africa: a qualitative investigation. *AIDS Care* 2010;22(8):970-78.
8. Cluver L, Orkin M, Boyes M, et al. Pathways from parental AIDS to child psychological, educational, and sexual risk: developing an empirically-based interactive theoretical model. *Soc Sci Med* 2013;87:185-93.
9. Joint United Nations Programme on HIV/AIDS. UNAIDS report on the global AIDS epidemic 2013. http://www.unaids.org/globalreport/global_report.htm. 2013. Accessed October 18, 2013.
10. Bwirire LD, Fitzgerald M, Zachariah R, et al. Reasons for loss to follow-up among mothers registered in a prevention-of-mother-to-child transmission program in rural Malawi. *Trans R Soc Trop Med Hyg* 2008;102(12):1195-1200.
11. Freeman M, Nkomo N. Guardianship of orphans and vulnerable children: a survey of current and prospective South African caregivers. *AIDS Care* 2006;18(4):302-10.
12. Lombe M, Ochumbo A. Sub-Saharan Africa's orphan crisis: challenges and opportunities. *Int SocWork* 2008;51(5):682-98.
13. Yeap AD, Hamilton R, Charalambous S, et al. Factors influencing uptake of HIV care and treatment among children in South Africa: a qualitative study of caregivers and clinic staff. *AIDS Care* 2010;22(9):1101-07.
14. United Nations Educational, Scientific, and Cultural Organization (UNESCO). International technical guidance on sexuality education: an evidence-informed approach for schools, teachers and health educators. 2009. Paris, France: UNESCO.