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‘That’s what I see’: Enhancing AIDS intervention research through deep ethnography

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Abstract

This research is based on 13 months of ethnographic fieldwork conducted in rural Lesotho, Africa between 2007 and 2009. The article shows how cultural competence in intervention research can be improved through ethnographic fieldwork, borrowing primarily from anthropological research protocols. Through an exploration of the challenges of caring for AIDS orphans and children with HIV/AIDS, I demonstrate that deep ethnography is an effective way to gain the necessary in-depth cultural insight, particularly in the initial design stages of culturally competent interventions. This is particularly true for rural or remote communities where structural barriers, such as poverty, are pronounced. This interdisciplinary approach provides both valuable information for those interested in orphan care in rural sub-Saharan Africa, and also demonstrates the importance of the ethnographic approach for intervention research in social work.

Keywords

Africa, ethnography, HIV/AIDS, intervention, orphan care

Introduction

This article uses *deep ethnographic* methods to gain cultural insight into the challenges faced by caregivers of AIDS orphans in rural Lesotho in order to contribute to more effective interventions that support caregivers. Lesotho, a small mountainous country surrounded by South Africa, has an HIV prevalence rate of 23.6 percent among adults, the third highest rate in the world (UNAIDS, 2008). One of the greatest problems emerging from the AIDS pandemic in Lesotho is its impact on children. UNAIDS estimates that there are 110,000–120,000 AIDS orphans

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in Lesotho; of these children, 12,000 are HIV-positive (UNAIDS, 2009). Lesotho has strong extended family ties, which, in the past, have worked to ensure that children were cared for in times of need. However, HIV/AIDS has created new challenges for families as the number of healthy adult caregivers has decreased and the number of children in need of care has increased (Foster et al., 1995; Guest, 2003). Based on 13 months of fieldwork, this study examines the challenges faced by caregivers of AIDS orphans and HIV-positive children in rural Lesotho. My findings confirm the essential role that caregivers play in the health and well-being of children. Thus, interventions that support caregivers are of the utmost importance in addressing the needs of AIDS orphans.

Borrowing primarily from anthropological research protocols, this article also demonstrates that culturally competent interventions to support caregivers can be improved by undertaking what I will call *deep ethnography*. Ethnography is a locally specific method of research that uses direct observation and other methods to capture the emic – or insider – perspective of a specific population or group (Bernard, 2006; Padgett, 2008). The empirical evidence derived from long-term immersion produces a unique kind of relationship building, insider cultural knowledge and the observation of people in a variety of social contexts over time that can greatly contribute to intervention research.

I distinguish between ethnographic methods and deep ethnography by asserting that the latter necessitates a variety of approaches including participant observation, semi-structured interviews, extensive field notes (Bernard, 2006), and long-term immersion in a community. The use of isolated ethnographic methods, such as semi-structured interviews, can produce decontextualized knowledge (Briggs, 1986). Instead, ‘deep ethnography’ refers to the type of ethnographic field work that anthropologist Clifford Geertz (1973) encouraged. Geertz’s idea of ‘thick description’ necessitates deep exploration of human experiences in their cultural contexts from multiple points of view. Although Geertz did not use the term ‘deep ethnography’ himself, his work has been influential in guiding ethnographic research in anthropology. The term ‘deep ethnography’ has been used by other scholars to distinguish long-term engagement in fieldwork of the type Geertz describes over newer appropriations of ethnographic methods in a more limited form (Pryor, 2004; Ulrich, 2004).

Thomas and Rothman’s (1994) categorization of intervention research is useful in understanding how this work fits into the spectrum of intervention research in human services. This study is part of what the authors call Knowledge Development (KD), which is defined as ‘empirical research to extend knowledge of human behavior relating to human service intervention’ (Rothman and Thomas, 1994: 3). Although KD research can look much like work coming from other types of social science research, it is distinct in that it is oriented towards finding solutions to problems that arise in human service fields. My explicit goal in undertaking deep ethnographic fieldwork was to better understand the challenges that caregivers of AIDS orphans in this particular social, cultural, and political economic context face, in order to make recommendations for interventions that could

improve the health and well-being of the children and caregivers. As Thomas and Rothman note, KD research provides an important foundation for this type of work (1994).

Kinship care and ethnography: A call for cultural competence

It is widely agreed that kinship care is the most effective and appropriate form of care for AIDS orphans in southern Africa because it allows children to preserve cultural values and customs and helps to maintain socially and economically important extended family ties (Young and Ansell, 2003). However, the quality of care that AIDS orphans receive is affected by the political, social, and economic context in which it exists. Research has demonstrated a correlation between the quality of care and morbidity (Foster and Williamson, 2000), as well as access to education, health services, nutrition, and emotional support (Loening-Voysey and Wilson, 2001). In Lesotho and throughout southern Africa, HIV/AIDS has influenced patterns of orphan care (Heymann et al., 2007). Townsend and Dawes (2004) warn that the death of parents and the reduction of healthy caregivers caused by HIV/AIDS may bring about a saturation of care networks so that kinship care of orphans is no longer a viable solution.

Caregivers living in rural southern Africa constitute what Abrams (2010) calls a 'hard to reach' population and HIV remains a highly stigmatized topic. Therefore, cultural competence is essential in order to develop knowledge and design interventions that meet the needs of the population. Culturally competent research in social work requires awareness about the ways in which cultural factors and differences alter our research topics and methods as well as our interpretation of the findings so that our research is useful and applicable to the cultural group that is being studied (Rubin and Babbie, 2001). These principles hold true for intervention research, and are particularly important for qualitative research methods like ethnography that involve extended interaction with research participants.

Interventions have evolved to increasingly address contextualized cultural elements of HIV/AIDS and have explored solutions through community participation (Foster et al., 1996; Kidman et al., 2007). Increasing cultural competence has facilitated a belated response to the need for effective treatment regimens, as well as support for patients' families and caregivers (Epstein, 2007). There is a positive trend evident in the HIV/AIDS intervention literature towards a community-based approach, using local populations for design and implementation (Drew et al., 1998; Foster et al., 1996; Higginbotham et al., 2001; Kidman et al., 2007). Scholars widely acknowledge that communities have culturally specific needs in coping with the effects of HIV/AIDS (Kidman et al., 2007; Oleke et al., 2007; Thurman et al., 2008). Cultural differences even within small geographic areas can produce differentiated responses that can impact the spread of HIV, both positively and negatively (Uneke et al., 2007). A nuanced understanding of these factors can be best understood through a deep ethnographic approach.

Ethnography is a useful research method for qualitative social workers because, as many have noted, the skills needed for ethnographic work and social work have a great deal of overlap (Archer, 2009; Gilgun, 2010; Goldstein, 1994). As Goldstein notes, ethnography and 'humanistic' social work both 'strive to appreciate the human experience as it is lived, felt, and known by its participants' (1994: 44). Gilgun speaks directly to the benefits of ethnography for intervention planning and design, arguing that the method provides 'the theory and knowledge about policies, problems, and practices that are required for the development of intervention research' (2010: 296). Two of the main tools used by ethnographers are semi-structured interviews and extensive ethnographic observations. Both of these techniques are useful specifically for intervention research because of the level of deep cultural knowledge and detail, and the contextualization of the human experience that they afford (Gilgun, 2010).

Social workers have long recognized the value of the ethnographic approach in studying marginalized populations (Floersch, 2002; Hall, 2003; Iversen and Armstrong, 2006; McClelland and Sands, 2002). However, limitations of time and resources prevent the widespread use of deep ethnographic methods by qualitative social workers (Fortune, 1994; Gilgun, 2010). Fortune (1994) recommends that social workers borrow from others' ethnographic insights in order to gain the necessary cultural understanding for research and practice. However, it is unclear why other disciplines, such as anthropology and sociology, place increased value on such in-depth and longitudinal fieldwork compared to social work. One possible explanation is that in social work such time-consuming research is not supported by academic rewards such as publication, funding and promotion. Whatever the reason, social work research adheres to methodological structures whereby randomized controlled trials are considered the 'gold standard' and are at the top of the research chain while methods such as ethnography are 'demoted to the bottom of the evidential hierarchy' (Huxley et al., 2010: 424).

Methods

I conducted two months of preliminary fieldwork in June and July of 2007, and 11 months of dissertation fieldwork from October 2008 to September 2009. The fieldwork took place in Mokhotlong – a rural district of Lesotho – based out of Mokhotlong Children's Services (MCS). MCS is a small, local community-based organization (CBO) that supports AIDS orphans and vulnerable children and their caregivers. MCS receives clients through word of mouth and referrals from health care providers, village health workers, chiefs, and neighbors. They provide transportation and nutritional support, caregiver support, outreach services, and temporary institutional care in their safe home. I lived on MCS's grounds, which include offices, volunteer housing, and the safe home, which is a facility that temporarily houses and rehabilitates severely ill children or those who cannot find immediate placement with extended family.

I began my research by accompanying MCS's outreach staff to villages, and helping them collect basic demographic survey data for their database from approximately 50 caregivers. During this time, I became acquainted with and identified 21 caregivers for follow-up. I then conducted a series of three to five in-depth, semi-structured interviews with each caregiver over the course of the year. The sample was a criterion-based purposive sample (Patton, 1990) whereby participants were chosen based on meeting specific criterion – in this case, they were all caregivers for AIDS orphans receiving services. In order to provide a comparison group, I recruited five caregivers who were not MCS clients by asking participants if there were any other caregivers of AIDS orphans living in their village who might want to participate in my research. However, because of an ethical responsibility to help those in need to access services, two of these families eventually became MCS clients based on my referral.

Interviews were conducted in both English and Sesotho and were recorded using a digital audio recorder. I employed a research assistant who translated during interviews. In order to ensure the most accurate transcription, my research assistant and I transcribed the audio recordings word-for-word after the interview. The interviews consisted of open-ended questions about kinship and relationships, important life events, and caregivers' experiences in coping with HIV/AIDS and orphan care. I also conducted interviews with several other community members including HIV/AIDS counselors, hospital employees, MCS staff, traditional healers, chiefs, and religious leaders. In total, I conducted 105 interviews, which were on average 60 minutes in duration. Finally, I carried out ethnographic observations in hospitals and clinics, observed the delivery of community services to families, and attended community events such as HIV/AIDS awareness events, funerals, and weddings. In most cases, I tried to avoid taking field notes during observations with caregivers. Instead, I would jot down a few notes immediately after leaving a location, and dictate them later into voice recognition software, Dragon NaturallySpeaking, to ensure complete and detailed records. All research activities were approved by the University of Michigan's Institutional Review Board, and verbal or written consent forms were used.

The International Federation of Social Workers recommends an ecological approach to intervention research that recognizes the need to focus on the 'person-in-environment' (Hare, 2004). This ecological approach is consistent with both ethnography and social work. Accordingly, I structured my research activities in order to increase the value of the ethnographic evidence by initially observing service delivery to AIDS orphans for several months in order to build rapport with potential interviewees as well as increase my understanding of the problem on the ground before asking questions of a sensitive nature. I visited the caregivers at least two times prior to interviewing them. I then began my series of interviews with the most general and least personal material. I also spent time during each visit chatting with caregivers and playing with the children in order to directly observe care and increase the comfort level of the caregivers. By the time I interviewed the caregivers about sensitive issues such as HIV and the challenges of care, we had

been acquainted for the better part of a year and had built a trusting relationship. Their thoughtful, honest, and personal responses reflect this effort.

From the hundreds of pages of field notes and interviews I collected, I carefully analyzed and coded the empirical evidence line by line using the software program *ATLAS.ti* to easily organize and retrieve passages both in their original context, and grouped with other passages with thematic and topical similarities. I began with sensitizing concepts, or initial ideas that acted as a starting point for the analysis of my notes and interviews (Glaser, 1978; Padgett, 2008). These concepts are related to HIV/AIDS and the challenges of orphan care. After reading and re-reading the notes and interviews, I created a series of codes based on these concepts that were adjusted and narrowed. The codes fit into two basic branches: the socio-cultural branch relates to kinship, caregiving, social customs, and other aspects of everyday life in Lesotho; the bio-cultural branch is concerned with the intersections of the biomedical and cultural aspects of HIV/AIDS in this particular context. Although these codes were originally created for my dissertation research – a deep ethnographic examination of the challenges of orphan care in the context of HIV/AIDS in Lesotho (Block, forthcoming) – for this article, I focus on the following code files on orphan care: caring, gender, intergenerational care, kinship ties, fosterage, and orphans.

Findings: Challenges of care

In this section, I demonstrate how deep ethnographic investigation provides insights into the challenges of orphan care in three key areas: time, ideal versus practice, and intangible factors. I will briefly introduce each of these key areas and provide ethnographic evidence to demonstrate how the methodological approach was essential in knowledge development for interventions in this area.

Time

The context of a problem over time provides key insights into potential intervention strategies that could address the real needs of a community. The following example highlights how deep ethnographic methods were key to providing insights to culturally competent interventions that support caregivers. Matseli¹ was an HIV-positive three-month-old orphan when he moved from his grandmother's house to the MCS safe home, where he spent almost a year. When he arrived at MCS, Matseli was severely malnourished and in need of treatment for HIV and tuberculosis (TB). Although his grandparents were competent caregivers, he was in need of monitoring and care that was difficult to achieve in a village setting, particularly one several hours from any medical facility. At MCS, he completed his TB treatment, successfully started antiretroviral medication (ARV's), was given special medical attention for a heart condition, and received nutritious foods that helped him thrive. Once his condition was stable, Matseli was reunited with his maternal grandparents and his four older siblings who were eager to have

him back. His grandparents took excellent care of him. In addition to being loving and affectionate grandparents, they went to the clinic whenever he was sick or needed medication, and adhered well to his complicated HIV treatment schedule. At 17 months of age, Matseli seemed to be an unequivocal success story. He was nursed back to health in a temporary residential facility and was reunited with his family who took excellent care of him with limited material and nutritional support from MCS. However, on Easter of 2009, two months shy of his second birthday, Matseli became sick with diarrhea and vomiting. His grandmother took him to a clinic – a two-hour walk away – but it was closed for the holiday. She returned the following day carrying Matseli on her back, but the child died on the way.

Even though his grandparents were affectionate, loving, and well versed in ARV care, he likely died of dehydration – a problem that could have been easily solved by drinking oral rehydration solution or, in the worst cases, with IV fluids available at the district hospital. After ongoing encounters with Matseli's family, one of my recommendations for intervention would point to the need for improved education for caregivers about treating symptoms of opportunistic infections such as diarrhea using limited resources, rather than merely understanding how to administer ARV's. If Matseli's grandparents had been trained to replace lost fluids with a simple oral rehydration solution consisting of boiled water, sugar, and salt, perhaps he would have lived. They could also have taken him to the district hospital, which is always open. However, they clearly did not understand the severity of the situation or how quickly an infant can die of dehydration. His grandmother expressed her surprise at his death, 'He wasn't even very sick. He didn't lose any weight. He was playing. I was getting Sesotho² clothes for him so we could take his photo... And he was so clever.' Sadly, I witnessed several instances of children dying because their caregivers did not know how to properly treat HIV-related illnesses or adhere to complicated treatment regimens. With antiretroviral treatments, HIV is now a chronic illness with long-term challenges that are unique to this specific cultural context. An intervention approach that has the benefit of observation over time is able to uncover more of the long-term challenges that caregivers face and make culturally salient recommendations for caregiver support.

The ethnographic approach was also an important rapport-building strategy. HIV-related stigma is still widespread, so relationship building was essential to acquiring honest and candid information from people. My relationships allowed me access into people's homes, I was given food, asked for advice, and in one case, I was even asked to speak at a child's funeral. As one HIV-positive woman told me, 'Families hide their news. For people to know that people have problems they tell people who they trust.' It was this trust building over time that led M'e Mapaballo, a 47-year-old woman and caregiver for her deceased brother's child, to tell me, unprompted, that she had recently been tested for HIV and found positive. This opened the door for a range of conversations between us that would not have been possible without a strong foundation of trust. M'e Mapaballo later told me about what she learned at her mandatory

adherence training. They explained to her that HIV is not curable: 'Ah, I asked them whether after taking the pills the infection will go away. They said no. But, the virus will not have power to work on my body.' She then asked me, 'Why do other people not get pills yet they are positive?' It is clear that even after her mandatory training, she still did not have a clear grasp of how the medication she was taking worked and the necessity of monitoring her viral load through a CD4 count (the standard method of assessing patients' HIV-stage in developing countries). This conversation, which was made possible by the relationship I had built with M'e Mapaballo, has straightforward implications for interventions to improve knowledge dissemination and AIDS education for those on medication, as well as those responsible for administering the treatment of HIV-positive children, and to include patient feedback to ensure that all aspects of the adherence sessions were understood.

Ideal versus practice

The gap that exists between ideal and practice can be understood through social practice theory (Bourdieu, 1977) which complicates the relationship between cultural ideals and practical negotiations that people make in everyday life. In application, this means that what people say can be different from what they actually do, and that a combination of observation and dialogue provides a more complete picture. This gap becomes evident if you ask Basotho about who makes a good caregiver for children. The unanimous answer is that women provide the best care. One middle-aged woman summarized the cultural ideal of the gendered division of labor like this: 'The job of women is to take care of the children and to cook and do all the cleaning in the house and gather wood. We wash the babies and wash the clothes for them. The father's duties are to plow the field and do any other jobs that can bring in money to the household.' In reality, I observed this – and many other – women partaking in typically 'male' activities, such as doing contract work for the government and working in the fields. Another elderly grandmother told me, 'The mothers are the ones taking care of the babies. There are few fathers who can... If the orphans can stay only with the father, you would not find them clean. They would always be dirty. But with the mothers, they will always be clean.' Although good male caregivers are less common, they do exist (as, of course, do inadequate female caregivers).

For example, Ntate Kapo's wife had left him when their two children were very young. He raised his children primarily on his own, with occasional help from his mother. When his daughter returned to his home a few years ago dying of HIV, he knew how to care for her two young sons, one of whom, Kotsi, is also HIV-positive. I asked Ntate Kapo's elderly mother about his relationship with the boys, she said: 'Yes, he is taking good care of them, and they are two boys. And he's taking very good care of them, *kanete* [I swear]. Very good care. He is like a woman in the household. He is cooking and he wakes up early to fetch some water and he washes them and the older brother goes to school.' I asked

Ntate Kapo (NK) about his role as caregiver, and he also commented on the gendered nature of his responsibilities:

NK: It seems like I'm his mother and he doesn't know his mother. He just knows that his mother is me. Sometimes he asks me, he says, 'Ntate, are you my mother?' . . . And he's young. He doesn't understand when people are saying his mother is dead.

EB: Why do you think he thinks you're his mother?

NK: It's because he has seen that I am taking care of him, and I'm taking good care, and I'm cooking, and I'm giving him food, and I wash clothes for him, I'm doing everything with him, and I sleep with him in the bed.

Caregiving is so intertwined with gender that Kotsi equates care with motherhood. Despite the strength of this cultural ideal, there are men, like Ntate Kapo, providing excellent care for children. The high HIV-rates and AIDS-related deaths in Lesotho and elsewhere in southern Africa have limited the number of available caregivers for orphans (Ansell and Young, 2004; Wood et al., 2006). My deep ethnographic fieldwork allowed me to recognize that the strong cultural ideal of a preference for female caregivers might ignore a potentially important resource in male caregivers. I would, thus, recommend an intervention strategy that helped to mobilize male caregivers in this population, avoiding the institutionalization of orphans when no female caregiver is available. Further, in the same way that Ntate Kapo discussed his role of caregiver as motherly, I would recommend an approach to recruiting male caregivers that engaged with the discourse of the cultural norm in order to be heard.

Intangible factors

The intangible insights that can be gained using deep ethnographic methods are the most challenging to describe precisely because they are, by their nature, difficult to grasp. They are not always physical or easily identifiable, but are nonetheless important in understanding the full context of a problem. These intangible issues are revealed through deep ethnography because the researcher is able to observe people in various environments, in multiple interactions with different people, participating in a variety of activities over time. The following examples, which describe some of the challenges of identifying caregivers for AIDS orphans, bring to light some of these intangible issues with regard to the qualities of a good caregiver, and the role emotion and affection play in caregiving.

Sinte Maphoto is the managing director of MCS and was born and raised in Mokhotlong. Her responsibilities at MCS provide her with insight into hundreds of families caring for AIDS orphans. We had many frank discussions about the challenges of service provision for this population, enabled by the close friendship we formed over the years. I raised with her the possibility that perhaps family members

did not want to care for children who were HIV-positive because of stigma surrounding the illness. However, she believed it was more likely related to limited household resources:

People don't really want to take care of smaller children. Especially if it's your brother's kid, or something like that. They do it, but very reluctantly. I wouldn't say it's because of HIV, I think it's just because of the load you already have. But, I don't know. I'm assuming, because they never say, 'Oh I don't want to take this kid because it's HIV positive.' But you see, 'Oh, how am I gonna feed this baby?' 'Oh, I already have my kids.' Things like that. That's what I see being the factor in people caring for other siblings' kids, or extended family's kids. It's hard to justify if it's stigma, or just because of poverty. Because you really don't have anything to provide for extra kids in your household.

M'e Maphoto unwittingly identified the key difficulty in crisis fostering, which entails the involuntary movement of children to households that need to stretch their resources in order to care for that child (Guest, 2003; Townsend and Dawes, 2004). She attributes the reluctance to foster orphans to a lack of resources. As death and illness among the adult population rise as a result of HIV, crisis fostering becomes more prevalent, and the need for interventions to support caregivers to address the impediment of resource shortages becomes more important.

One question that defies a concrete answer is, what does it mean to be a good caregiver for an AIDS orphan or HIV-positive child? There are, of course, certain physical attributes of good care. In fact, Basotho place high importance on physical aspects of care because they are easily identified. When caregivers were asked about what a child needs for proper growth and development they emphasized food, clothing, and cleanliness. Basotho tend to emphasize these physical aspects of care because, in general, they are more comfortable discussing material and observable aspects of their personal lives over emotional ones. For example, when I asked caregivers about the benefits of caring for the orphans in their household, they emphasized the ways in which the children helped them with chores. M'e Matau is a grandmother responsible for four AIDS orphans from two deceased and unmarried daughters. Although there is obvious affection between M'e Matau and her grandchildren, she also likes having them around because they are useful, a fact she does not mind admitting. She says, 'I like them to help me because I have been caring for them.' It would not make sense for me to ask, 'But, do you love them?' A deep ethnographic approach helped me to recognize the folly in this type of question, while at the same time, gave me insight into the answer. As I witnessed over time, the best caregivers were very loving and affectionate towards their grandchildren, and these tended to be grandparents.

I observed numerous signs of love and affection between grandparents and grandchildren during my fieldwork. For example, I observed Matseli's grandmother sing a song of joy for him when he returned from the MCS safe home. Likewise, six-year-old Kotsi and his grandfather were inseparable. On one visit

I remember observing him playing energetically outside his hut near where we were talking. Every so often Kotsi would take a break from playing just to stand by his grandfather and put his hand on his knee in order to momentarily connect with him, and then return to playing. In light of Basotho's tendency to focus on the physical over the emotional in interviews, deep ethnographic methods allowed me to witness this special bond.

Grandparents, particularly grandmothers, increasingly find themselves as the only viable caregivers because of AIDS-related illness and death. The cultural expectation of affection between grandmothers and grandchildren helps to protect and maintain strong intergenerational bonds during this difficult time for caregivers. Because of this, a disproportionate number of grandmothers are providing care for their orphaned grandchildren. Often this care requires them to work beyond their physical and material capabilities, thus creating loving but vulnerable homes for children. These encounters and observations highlight the tensions that exist between a caregiver's physical and emotional ability to provide adequate care. They contribute to a greater understanding of what makes good caregivers. Recommendations for intervention should attempt to maximize this affectionate relationship between grandparents and grandchildren that is both real and culturally salient, while addressing the challenges of orphan care specifically associated with the age of the caregiver. It is worth investing resources to help elderly caregivers support the orphans in their care as well as maintain their own health. Elderly caregivers provide important physical and emotional support to AIDS orphans that is essential to their health, well-being, and happiness.

Discussion and implications

The primary purpose of this article is to demonstrate the importance of deep ethnographic methods for knowledge development in intervention research. However, the ethnographic examples presented also provide important insights into the challenges of orphan care. Therefore, the following section will address both intervention and methodological implications for research and practice.

Intervention implications

This article focuses mainly on knowledge development, one of the phases of the Rothman and Thomas (2004) model of intervention research. In this regard, I want to address the methodological issues that arise in social work research in the area of knowledge development. The empirical evidence presented here is primarily in service of illuminating the ethnographic methods used in this study. I present the ethnographic data in more detail elsewhere (Block, unpublished manuscript). However, even this limited glimpse points to the importance of supporting caregivers in order to ameliorate the health and well-being of AIDS orphans in rural southern Africa. This finding relates to knowledge utilization in the Rothman and Thomas model.

Caregiver education is of the utmost importance, and this education should include basic treatment guidelines for children who are on antiretroviral treatment, as well as information about the treatment of opportunistic infections such as dehydration associated with diarrhea. Information on signs and symptoms of life threatening problems should be clearly delineated so caregivers know when it is necessary to make the expensive and sometimes arduous trek to a health facility. Dissemination is part of the design and development phase of the Rothman and Thomas model. As professionals develop programs for the care of AIDS orphans and the support of caregivers, they should investigate the efficacy of various methods of information dissemination in this cultural context such as group educational workshops, peer counseling, and demonstrations of important skills related to care. They should also be aware of how cultural factors such as literacy, culturally appropriate methods of communication, gender roles and dynamics, power structures, and AIDS stigma could be integrated into design and development and then monitored for effectiveness. The results of this phase of intervention research would be used to modify the intervention.

As networks of available caregivers narrow with the progression of HIV/AIDS, and in particular, as the current community of elderly caregivers is no longer capable of providing adequate care for AIDS orphans, intervention strategies should include seeking untapped resources of potentially good caregivers. In particular, I observed several instances of men providing excellent care for AIDS orphans despite the cultural ideal that men cannot care for young children without the support of a woman. In addition, efforts to find adequate caregivers for AIDS orphans should look not only for those capable of providing for the physical needs of the children, but also for their social and emotional needs. I found that elderly caregivers provided excellent social and emotional support for AIDS orphans; therefore, efforts to enhance their ability to provide for the physical needs of orphans are important in the design and development of interventions.

Intervention strategies should work to strengthen local community-based organizations (CBO), which are best equipped to respond to the needs of community members, and already have networks in place to deliver the necessary services (Drew et al., 1998; Kidman et al., 2007). CBO's are particularly well-suited to understanding the nuances of cultural ideals versus everyday practice, and to have a sense of the intangible factors that might prevent intervention strategies from being successful. Interventions should be designed not only for implementation by CBO's, but should be designed in collaboration with local employees of these organizations for maximum impact.

Methodological implications

This research revealed three key methodological strengths of a deep ethnographic approach: time, ideal versus practice, and intangible factors. These strengths make deep ethnography an important strategy for developing knowledge needed to design interventions with marginalized populations on sensitive issues.

Time allows researchers to grasp the full context in which a problem exists, and is imperative in relationship building so that the researcher can broach sensitive topics and hope to elicit sensitive, thoughtful, and honest insights. Such prolonged engagement in the field has promise of providing in-depth information from research participants' points of view. Such information is foundational for the development of effective interventions. This research took place over 13 months, which was just sufficient for the Knowledge Development phase of intervention research. Those interested in developing and testing interventions should plan a longitudinal study including multiple visits and the testing of preliminary interventions over time. Time was the linchpin of this research because, in addition to having its own intrinsic value, it was also essential in uncovering the other key strengths revealed by this study.

The deep ethnographic approach helped to reveal the dialectic relationship that exists between cultural ideals and actual practice. Understanding both helps to illuminate cultural norms, as well as ways that intervention strategies might fail or succeed despite stated cultural norms. Finally, intangible factors play a large role in social responses to a problem. They cannot be asked about, as they are often so deeply embedded in the cultural context that they are only revealed through observation and cultural immersion. One limitation of this methodological approach is that many of these intangible factors are beyond the grasp of an outsider, despite longitudinal study, because we come with our own cultural biases. This merely reinforces the importance of collaborating with local scholars and CBO's for the implementation of intervention research, because their local knowledge and expertise will always be far more substantial and nuanced, regardless of the length of study.

Conclusion

As the empirical evidence described in this article has demonstrated, the physical, material, and emotional challenges of care for an AIDS orphan or HIV-positive child in Lesotho are numerous and manifest themselves in different ways over time. Sustainable solutions to these challenges are embedded in the community, and necessitate a high level of cultural competency. Researchers in similar communities can achieve cultural competency through observation and relationship building over time, can gain an understanding of both cultural ideals and everyday practices, and can acquire insight into the intangible but important aspects of caregiving for AIDS orphans that only cultural immersion reveals.

Ethnography creates localized and context-specific intervention approaches (Schensul et al., 1999). Yet these approaches can be used and built upon through additional ethnographic investigation, to create local theories tailored to other communities with similar problems and populations. Therefore, others interested in the care of AIDS orphans in rural African communities can build upon a body of ethnographic work in useful and locally-specific ways. Such an approach could greatly strengthen intervention research for hard-to-reach populations, particularly

during the knowledge development stage of the research process. For example, this research sensitized me to the importance of gender ideologies in influencing community responses to AIDS orphans. Such knowledge provides insight into other cultures and could be tested for fit in other rural southern African communities with high rates of HIV infection. Those who develop interventions would do well to pay attention to the role that gender plays in shaping cultural expectations about men's and women's roles as caregivers.

This article has demonstrated the value of deep ethnographic approaches, particularly with regard to sensitive issues in remote, rural communities. Considering the fit between ethnography and social work and its usefulness in understanding social problems, the institutional barriers that social workers face in conducting research using deep ethnographic methods, such as limited time for research, tenure and publication requirements, and available funding and other resources, need to be adjusted to facilitate this important approach.

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1. All names are pseudonyms to protect the identities of the research participants.
2. Sesotho is used to refer to the language as well as the culture of the Basotho people.

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