

College of Saint Benedict and Saint John's University

DigitalCommons@CSB/SJU

Sociology Faculty Publications

Sociology

5-2018

Living, dying, after death: Achieving a "good" death in the time of AIDs orphan care

Ellen Block

College of Saint Benedict/Saint John's University, eblock@csbsju.edu

Follow this and additional works at: https://digitalcommons.csbsju.edu/sociology_pubs



Part of the [Anthropology Commons](#)

Recommended Citation

Ellen Block (2018) "Living, dying, after death: Achieving a "good" death in the time of AIDS orphan care", *Death Studies*, 42:5, 275-281, DOI: [10.1080/07481187.2017.1396396](https://doi.org/10.1080/07481187.2017.1396396)

This is an Accepted Manuscript of an article published by Taylor & Francis in *Death Studies* on May/June 2018, available online: <https://doi.org/10.1080/07481187.2017.1396396>.

**LIVING, DYING, AFTER DEATH: ACHIEVING A “GOOD” DEATH IN THE TIME
OF AIDS ORPHAN CARE**

ELLEN BLOCK

College of St. Benedict & St. John’s University

Living, dying, after death: Achieving a “good” death in the time of AIDS orphan care

Ellen Block

Abstract:

AIDS has devastated communities across southern Africa, leaving many children orphaned. Grandmothers are considered ideal caregivers because of cultural expectations of intergenerational care, and because they have not been decimated by AIDS to the same extent as younger adults. However, these grandmothers, who currently carry the majority of the burden of care for AIDS orphans, are themselves aging and dying. I argue here that in Lesotho, the caregiving demanded of grandmothers late into their lives not only alters kin relations for the living, but has increasingly made a “good death” unachievable for elderly caregivers.

Introduction

AIDS has devastated communities across southern Africa. In Lesotho, where a quarter of the adult population is infected, the wide reaching implications of the disease have disrupted every aspect of social life. One area of particular concern is the fate of children orphaned by the epidemic. Thus far, kin-based care for AIDS orphans has been facilitated by culturally salient and historically prevalent intergenerational child fostering practices across the continent (Bledsoe, 1990; Goody, 1984; Burman, 1996; Whyte, Alber, & Geissler, 2004). Grandmothers are considered ideal caregivers for orphans in southern Africa both because of the cultural expectation that they will provide care and affection, and because they have not been decimated by AIDS to the same extent as the “missing generation” of sexually active adults. However, these grandmothers, who currently carry the majority of the burden of care for AIDS orphans, are themselves aging and dying. While numerous studies have documented the important role

that grandmothers have played in providing kin-based care for AIDS orphans (Cook et al., 2003; Nyesigomwe, 2005), and some have addressed the challenges unique to elderly caregivers in Africa (Drah, 2012; King, 2008; Guest, 2003), researchers have yet to address the impending threat of the deaths of grandmothers who are themselves caregivers. While grandmaternal death is having a significant impact on care for orphans, it is also changing the meaning and experience of dying elderly caregivers in Lesotho.

The anthropological study of death, while prolific, has been characterized by an interest in the ritual practices and meanings that surround the dead person's body and soul, the funeral, the mourners, and the production of ancestors (Kaufman & Morgan, 2005). A number of studies have addressed how the meaning and circumstances surrounding death have changed in the context of AIDS in Africa; however, these primarily focus on the socially constituted experiences of those dying of AIDS (Russ, 2005; Farmer, 1999; Dilger, 2008; Niehaus, 2007; Klaitz, 2010). In rural Lesotho, the caregiving demanded of grandmothers late into their lives not only alters kin relations for the living, but has made it difficult to achieve a "good death," even for those not living with, and dying of, AIDS (Johnson, Cook, Giacomini & Willms, 2000; Van der Geest, 2004).ⁱ In Van der Geest's (2004) study of death in Ghana, he finds that a "good death" is often cross-culturally characterized as peaceful, natural and accepted both by the dying and by those left behind. However, in Lesotho, many grandmothers caring for AIDS orphans worry about what will happen to the children in their care after they die. They express a desire to prolong death; as one grandmother of four orphaned children told me, "I'm always praying to God to help me so that I can live for a long time and [the children] should be old enough to do things for themselves." HIV/AIDS has increasingly made a "good death" unachievable for elderly caregivers in Lesotho.

In this paper, I examine the transition from grandmother care to grandmother death. I argue that the experience of preparing for death and the accompanying shifts in social relations and caregiving that ideally should accompany this transition are falling short. The time, care and other supportive resources necessary to achieve a “good” death are no longer available to many grandmothers in Lesotho. Death, like most rites of passage, is ideally a process where the dying person attends to their material and social affairs, readying themselves for a peaceful and accepted passing (Van der Geest, 2004; Mimica, 1996; Graham, Gwyther, Tiso & Harding, 2013). However, this transitional period of dying, under the pressure of AIDS, seems to be calcifying to a moment wherein grandmothers are needed to care for children until the time of their deaths. It is only after a grandmother dies – often at her funeral – that the familial negotiation process to maintain kin-based care for the children begins. Only then does the necessity and difficulty of the work needed to maintain kin networks through care become visible, moving beyond what to that point had been primarily the responsibility and the internalized anxiety of the grandmother.

In order to explore the shifting experience of death for Basotho grandmothers, I present the detailed cases of three families at different stages of this process: I follow a living grandmother, a dying grandmother, and a child after the death of her grandmother. These three cases reflect the widely held anxieties, fears, and hopes of grandmothers for their grandchildren, the insecurity and speculation of those who appear to be near death, and the period of child circulation that often occurs after the death of a caregiving grandmother. I show how the experience of dying has been transformed for grandmothers, orphans and caregivers by the physical and material demands of caring for AIDS orphans, thus altering social networks and caregiving relationships for the living, while also changing the meaning of death for grandmothers in Lesotho. While I have addressed the ways in which social networks have

shifted to accommodate a large orphan population at the family level elsewhere (Block, 2014; 2016b), in this paper I focus on grandmothers' experiences as they near the end of their lives and the consequences for their families after their deaths.

AIDS Care and the Changing Experience of Death

The AIDS pandemic in southern Africa has had a transformative effect on social relations. This stems not only from the intimate ways in which HIV spreads between sexual partners and between mother and child, but because of the myriad ways in which AIDS infirmity and mortality alters networks of care. Care and kinship are deeply linked as moral practices not because they are self-evident but precisely because they are complicated by affective ties that exemplify the “ambivalence of intimate experiences” (Carsten, 2013, p. 7). Two areas of altered care relations have been widely studied in this region: care for the dying AIDS patient, and care for AIDS orphans. Most obviously, those dying of AIDS need intensive care provided primarily by kin and complicated by poverty, limited treatment options, and stigma (Niehaus, 2007; Chimwaza & Watkins, 2004). In the wake of high AIDS mortality among the middle generation of adults, AIDS orphans further altered caregiving relationships as families stretched their resources to find a home for children within the extended family network (Nyambedha, 2003; Madhavan, 2004; Abebe & Aase, 2007). Much of this care has been left to grandmothers who are ideal caregivers for both cultural and economic reasons (Block, 2014). There exists an idealized cultural expectation that grandmothers will provide the best care for grandchildren; as several Basotho said, they will care for their grandchildren “like a mother”. More pragmatically, grandmothers are typically no longer engaged in wage labor, and are therefore available for full-time caregiving duties without reducing the family's household income. One underexplored aspect of AIDS' impact on caregiving relations is the almost invisible loss of caregivers for the elderly, many of whom are instead providing care for children well past their physical and

material capacities (Foster, 2000; Bock & Johnson, 2008). This inevitably alters the experience of aging and dying in ways both physical and psychosocial. In particular, the process of death is abridged or eliminated, the acceptance of death becomes secondary to care, and the direction of care from the young to the elderly is reversed.

Like other aspects of kinship, death is a process. Death does not merely occur at a moment in time, but in many cultures includes the period leading up to death, and continues after death as a person undergoes funeral rites and takes on the role of an ancestor (Kaufman & Morgan, 2005; Hertz, 1960). If one is fortunate enough to not die an untimely death, the period of infirmity leading up to death is used to make amends and prepare for death. While an important ritual, the funeral is only one part of the dying process and does not necessarily mark the end of a person's social existence. For Basotho, rituals at the funeral help a person transition from a living member of the kin group into an ancestor. Despite the significant financial burden of funerals for many families in the context of high AIDS mortality (Nyambedha, 2003; Collins & Liebbrandt, 2007), a funeral ceremony and feast is essential, according to several Basotho interlocutors, in order to “accompany a person to the grave”, and ongoing ancestor rituals and offerings ensure that the ancestors continue to work on behalf of their kin (Graham et al., 2013). As Graham and colleagues emphasize, it is essential to ensure good relations between the living and the dying because “the dead continue to live, unseen by the living” (2013, p. 392). The rituals that surround a person's death are thus not merely a matter of etiquette or custom – they are deeply moral issues.

Dying is a locally situated process, mediated by history, culture, political economies, and available technologies. As the context changes, so does the dying process. For Basotho grandmothers caring for orphans, the dying process has been abridged to a moment, and the appropriate reparations and preparations necessary to achieve an ideal death have become

unattainable. Elderly grandmothers I spoke with viewed themselves as essential caregivers with a crucial role in maintaining the family. Even though they sometimes negotiated for the right to care for their grandchildren, and often found the carework gratifying, the burden of caring for, and worrying about, their grandchildren, made it impossible for aging Basotho women to attend to their own physical and social needs and to prepare for their own deaths.

The economic and social consequences of AIDS mortality and orphaning make a “good” death difficult for caregiving grandmothers to achieve. One common theme that characterizes a “good” death across cultures is acceptance (Van der Geest, 2004). The notion of acceptance is particularly relevant given the rise in chronic diseases such as AIDS and cancer, which often come with poor prognoses for patients yet with extended illnesses leading up to death (Green, 2012). According to Klaitz (2010), acceptance of death among Pentecostal Christians in Botswana is linked to faith in God. Baswana are expected to demonstrate this acceptance by leaving instructions for those left behind (Klaitz, 2010). Just as those dying are expected to accept their impending death, so are their loved ones. In Namibia, it is the responsibility of the dying person to maintain a positive attitude and ensure that their family and friends are not worried about them (Powell et al., 2014).

In Lesotho, AIDS mortality and caregiving responsibilities make acceptance of death difficult for many grandmothers. Caregiving grandmothers routinely told me that they had a great deal of anxiety about what would happen to their grandchildren after they died. Far from accepting their deaths, grandmothers and other members of the family feared grandmaternal death because of the social and material consequences for the children in their care and for the rest of the family who would have to take on the additional caregiving burden. A “good” death is a social process and decision making about end of life care should be a social task shared among family members (Powell et al., 2014). However, the uncertainty of life in Lesotho meant

that the majority of grandmothers I spoke with had made minimal, if any, preparations or plans about who would take the children in their care because it was impossible to predict who would still be available when the time came due both to high rates of mortality and labor migration.

Age is also a significant factor in one's ability to achieve a good death. Untimely death is considered "bad" while an elderly person who dies at home surrounded by loved ones is considered "good" (Van der Geest, 2004). The idealized vision of aging and dying in Africa, where an elder no longer has the physical capacity to partake in agricultural or wage labor activities, yet has important moral social functions within the family, acknowledges that elderly people have ailing bodies in need of care (Buch, 2015). Pension plans, which provide cash to the elderly in many southern African states, are intended to contribute to the care of the elderly and compensate for their loss of labor. Yet, as Livingston notes, pension plans, which vary in their age requirements and distribution amounts, essentially put an age on aging (Livingston, 2003). In Lesotho, anyone over the age of seventy is eligible to receive 500 Maloti per month (the equivalent of 35 US dollars). The arbitrary assignment of an age that entitles a person to receive aid from the state disregards the rise in chronic diseases in southern Africa where an elderly person might require support before they reach the age at which the pension is distributed (Buch, 2015). Arbitrary pension regulations also disregard the fact that many grandmothers are using their funds to support their grandchildren with little left to care for themselves (Schatz & Ogunmefun, 2007). Most grandmothers in this study noted that they regularly struggled to buy food, household basics, school uniforms, shoes, and pay for school fees with their pensions. By necessity, grandmothers were working well past their physical capabilities to care for orphans. They performed household labor, often including the care of sick or HIV-infected children, and often worked in "piece" jobs fixing roads, brewing beer to sell, or working in another person's field to make ends meet. Their government pensions, which are intended to support them in old

age, were in fact a key resource used by families to care for orphaned children which, paradoxically, made grandmothers over 70 particularly attractive as caregivers because of the promise of a small monthly wage. Elderly Basotho caregivers' own bodily decline and their need for care was often overlooked in these decisions.

As Klaitz argues, in Botswana, a good death was idealized as when “the elderly gradually became frail with accumulated wisdom and spiritual power, retaining supervisory roles in productive activities” (2004, p. 219). In Ghana, a good and peaceful death occurs naturally “after a long and well-spent life, after having solved arguments and conflicts, in the company of dear ones, without pain, while at peace with one’s own death” (Van der Geest, 2004, p. 909). Yet, the ideal is almost always contested, and as Carsten notes, can create “ruptures and continuities across generations” (2013, p. 7). A long history of entrenched migrant labor in the South African gold mines, where conditions were poor and infectious disease rates high, meant that many Basotho died unnatural and unexpected deaths while separated from their families, unable to perform the appropriate mortuary rituals (Maloka, 1998). The current context of high AIDS mortality and grandmaternal care is both an extension and intensification of a remittance economy that has long employed flexible household configurations to meet the caregiving needs of its members. The following case studies illustrate the experiences of caregiving grandmothers in Lesotho at different stages in the abridged dying process, and the reconfiguration of families that occurs after their deaths. Following local linguistic practice, I use the term grandmother (*nkhono* in Sesotho) to indicate an elderly female relative, typically a grandmother or great-grandmother, but sometimes an elderly aunt. While younger caregiving grandmothers in their 50s and 60s do care for orphaned children, in this paper, I focus on cases of grandmothers or great-grandmothers over 70 because of their increased need to receive care due to aging, and

because they are realistically contemplating the potentiality that their deaths might precede their grandchildren's independence.

Living: Nako's Story

"Cheese" I said, as I prepared to take a picture of Nako with his grandmother and aunt, in order to show the staff from a small NGO in Mokhotlong how much Nako had grown in the three years since they had seen him. "Wait, wait, *butle ausi*," his grandmother said. She whisked him inside and he came out wearing beige corduroy pants and a faux white fur coat. The three of them arranged themselves around a bench, Nako sidling up to his aunt and grandmother with gentle affection.

Four-year-old Nako has lived in three places during his young life. He spent his first four months with his mother and father in the home they had built after getting married. Shortly before his mother died, he lived for a year in a temporary care facility in the camp town of Mokhotlong. While there, he tested HIV-positive and started on antiretroviral treatment. Since 2010, he has been living with his paternal grandmother, 'M'e Maarone, who is 76-years-old, and suffers from chronic back and knee pain.

When I asked 'M'e Maarone if there was ever a conversation about who would take Nako after his mother died, she told me "Yes, they had a conversation and there is no chance to give Nako to other people because it is me who is taking responsibility...Nako is my grandchild. So no one can take care of Nako except me." Here she indexes both the tightening of networks of support, and the moral imperative for grandmotherly care that is framed as a "cultural" imperative. As another grandmother told me, "When the baby is in the family it is better because he or she is going to know their relatives and their culture."

While the love and affection between these two is obvious, caring for Nako presents challenges. 'M'e Maarone spells these out for me: "The difficulty is with food because

sometimes I used to give Nako [only] papa and *kholu* [water from cooking vegetables]... Those are the difficulties. Nako is waking up early and he is going up and down the village so sometimes Nako is not taking his medication well. Those are the challenges. I have struggles.” I inquired about Nako’s father who lives up the hill where ‘M’e Maarone used to live before her knees became too sore to make the trek. At first, she tells me: “*Ache!* The father is useless. Because, as you see, when I am struggling, he doesn’t care about it. I was asking him to find another ‘M’e to help me to do Nako’s washing and to bathe Nako and he didn’t say anything”. She later revealed that he did in fact take Nako to the clinic every month for his checkup and medication refill, and gave her money whenever he was able to find work. Yet her focus on the labor of care reinforces the importance of the physical acts of daily care in reproducing and shaping relatedness.

While speaking with grandmothers, I sought to understand the anxieties and plans of those who were nearing the end of their lives. Thus, I often found myself in the awkward position of having to ask caregivers to imagine their own deaths. In an attempt to broach this delicately, I asked ‘M’e Maarone, whom I had known for several years, “When you can no longer care for Nako, who is going to care for him?” In a sentiment that echoed that of many of the grandmothers I spoke with, she replied frankly: “I don’t know, I am asking myself about that all the time.” While formalized plans of this sort are rare, some, like ‘M’e Maarone have had informal discussions with kin. She said, “I was talking to my daughter and I said, ‘will you help me when I can’t help this baby?’ And she replied to me saying, ‘I don’t know, but I will.’ Later, she reflected: “I want the children to know their relatives. I don’t know if my daughter will agree, but she will agree when I am dying.” ‘M’e Maarone and others’ inability to make firm plans stems from the economic and social factors that characterize the shifting and fluid caregiving networks in Lesotho: including labor migration, health, age, and reproductive life

stage. While Nako's situation at the time of this research was a happy one, it was also underscored by the instability that is characteristic of aging and death in the context of AIDS care. M'e Maarone, whose health visibly deteriorated over the past few years of our acquaintance, lives with the burden of uncertainty and anxiety both about Nako's life and her own death.

Dying: Rethabile's Story

In contrast to Nako's relatively stable caregiving situation, 6-year-old Rethabile's life was characterized by insecurity and imminent death. Rethabile was living with his 92-year-old great-grandmother, 'M'e Masepono. When I first approached their house, 'M'e Masepono was lying in a sunny patch on the ground on a thin blanket outside her home, her arm flung limply across her eyes, her legs covered with flies. She awoke at the sound of our approaching feet and was unable to lift her head. I could barely make out her mumbled words as she told me her feet were hurting and she couldn't move. She said: "I want to die. I want God to take me so I will not be suffering anymore." She then asked me for some pills, so I produced a bottle of pain killers from my backpack. Ideally, 'M'e Maspono would be cared for by her own children and grandchildren. Instead, she lived alone with her young grandson, and despite her pain, had for a long time been chiefly responsible for his care. As her condition deteriorated, she solicited help from nearby relatives. She was in far too much pain to have a conversation with me that day, so I sat with her for a while, then left.

I returned another day to speak with Rethabile's aunt [*mangoane*] who lived in a house nearby in the same village. She hollered outside to her own grandchildren, "Where is Rethabile?" then told me, "He is always playing here." She told me that Rethabile's mother died of AIDS, and his father's whereabouts were unknown. As his great-grandmother's illness progressed, Rethabile's paternal grandfather - 'M'e Masepono's son - was doing much of the

daily carework for Rethabile. He had been taking Rethabile to his house to bathe him and wash his clothes for the past several months. The aunt also assisted with cleaning and washing. ‘M’e Masepono, though unable to stand without pain, was still responsible for cooking for both Rethabile and his grandfather, who was in his 70s. I asked the aunt where Rethabile would go when ‘M’e Masepono died. She told me that perhaps his grandfather would take him, though she added with a touch of skepticism, “But, [he is] a male person...”, thus reinforcing the strength of gendered notions of care, where men are considered a last resort (Block, 2016a). While there are others in the family, such as a maternal aunt and two uncles, they are reluctant to take him because the aunt’s husband does not want the child, and one of the uncles is already “burdened with orphans.” In contrast to ‘M’e Maarone, ‘M’e Masepono’s experience serves as a stark reminder of the ways in which AIDS has unsettled care relations so that there is no one to attend to her suffering.

After Death: Seipati’s Story

After the death of her mother in 2008, two-year-old Seipati and her two older siblings went to live with their paternal grandmother. Seipati was HIV-positive, and demanded much of her grandmother’s attention and care due to recurring illness. Seipati’s father was still alive at the time, and lived in the home he had shared with his wife and children. In Lesotho, in the absence of a mother, a grandmother is widely preferred over a father as the primary caregiver, as men are seen as inadequate when it comes to the daily acts of caregiving such as cooking and washing. After their mother died, the three children all relocated to their paternal grandmother’s house, though their father continued to visit them and support them financially when possible.

Seipati’s father died at the end of 2012, and his mother, Seipati’s paternal grandmother, died shortly afterward, at the age of 74. At that time, Seipati was seven-years-old and had been living with her grandmother for five years. After her death, Seipati’s two older siblings went to

live with their maternal grandmother. But, this grandmother had had a stroke, and was not able to care for Seipati, whose health had deteriorated during her paternal grandmother's illness.

Seipati's paternal grandmother had been chronically ill for a long time, but the period of intense illness near the very end of her life was brief. One of Seipati's aunts described the grandmother's decline:

She was sick for a long time, but she was going everywhere. Before she died, she became very sick for a short time. She suffered from asthma...*Ache*, she was sick but she was always looking after the child. But, *joale*...when did the sickness become heavy for her...? I think she took a week only, to be suffering. They took her to the hospital. When she arrived at the hospital, she died.

Seipati's grandmother was not able to rest and contemplate her death in the last years of her life. Instead, she pushed herself to provide for the needy child in her care, took her to clinic appointments when she was able, possibly even shortening her life in order to fulfill her caregiving duties. If a good death is, as Van der Geest (2004) suggests, natural, peaceful, and accepted, Seipati's grandmother's death was far from "good" for her or for her granddaughter who was left behind. After her grandmother's death, Seipati was forced to cope with her grief while adjusting to a series of relocations, the last of which took her away from the village where she had always lived. Seipati moved to the capital city, Maseru, a day's travel from her natal village, to live with a young maternal aunt. While this aunt was married, she did not yet have children of her own, thus increasing the possibility that Seipati will have to relocate again in the likely event that her aunt starts her own family.

Discussion and Conclusion:

AIDS is the leading cause of death in sub-Saharan Africa, and impacts the "social fabric" of communities (Howarth, 2007, p. 56). When an adult, especially a mother with children, dies

of AIDS, this has a ripple effect through the family. Financial and caregiving burdens result from the dying person as well as the children left behind. The loss of daughters for many grandmothers means both the loss of a caregiver for their old age, and the additional responsibility of raising their grandchildren. Paradoxically, while most elderly grandmothers discussed the challenges of caring for young children, they also relied on them to perform household chores such as collecting firewood and water, and they valued their companionship, particularly in light of the acute loss they felt at having lost their own child to AIDS. Many grandmothers mentioned how much they enjoyed having their grandchildren live with them, and worked hard to secure their position as caregiver, even as they felt anxious and overworked by the responsibility. One ailing grandmother, who regularly worried about her grandchildren's fate, told me that her grandchildren extended her life: "Ah, there would be no life...I'm just living because of these children." In some ways, grandmothers are seen as relatively stable caregivers from both a cultural and economic standpoint. Yet the aging and rapid transition to death for many of these grandmothers, and the subsequent need to reconfigure familial caregiving relationships, exposes the instability inherent in the life course in the context of high AIDS mortality and cultural expectations of grandmaternal care. Despite these ruptures, this work also shows that the "entanglements of emotion, care and kinship are very dense" and allow for the exceptional flexibility of kinship in providing continuous care for orphans in a wide array of relational arrangements (Carsten, 2013, p. 4).

In exploring the transition from grandmother care to grandmother death, I find that networks of care have been deeply unsettled so that ideal social and caregiving relations that should accompany this transition are falling short. Time, resources, and kin networks are depleted, transforming what was previously a processual transition to merely a moment - the moment of death. The aftermath of this moment is characterized by movement and insecurity for

the children. While plans for the transfer of care were occasionally discussed, as in Nako's situation, the kind of detail and planning one might expect for such an important transition was neither appropriate nor possible given the regularity of child circulation and the uncertainty of available caregivers. Grandmothers are increasingly required to care for children right until their deaths, as Seipati's grandmother did, and the anxieties around these tightening networks of kin are the sole responsibility of the grandmother until that moment of death, when they become the problem of the whole network of potential caregivers. Basotho grandmothers can no longer attend to their personal affairs or prepare for their deaths and are thus unable to attain a "good death" even as they are engaging in other important relational tasks by caring for their orphaned grandchildren. As such, caregiving grandmothers have opted to privilege one aspect of social reproduction (good care) over another (good death). Death for caregiving grandmothers in Lesotho has become distilled to a moment, shortening or eliminating the process of dying, and reversing the appropriate late in life direction of care from the grandmothers instead of for them.

Acknowledgements

I am greatly appreciative of the ongoing participation of my interlocutors in Lesotho. I would also like to thank Aaron Seaman and Janet Carsten for their comments and insights. This work was supported by a U.S. Fulbright Scholar Grant and by the Population Studies and Training Center (PSTC) at Brown University. The PSTC receives core support from the Eunice Kennedy Shriver National Institute of Child Health and Human Development (5R24HD041020).

References

- Abebe, T., & Aase, A. (2007). Children, AIDS and the politics of orphan care in Ethiopia: The extended family revisited. *Social Science & Medicine*, 64(10), 2058-2069.
- Bledsoe, C. (1990). 'No success without struggle': Social mobility and hardship for foster children in Sierra Leone. *Man*, (N.S.) 25(1), 70-88.
- Block, E. (2014). Flexible kinship: caring for AIDS orphans in rural Lesotho. *Journal of the Royal Anthropological Institute*, 20(4), 711-727.
- Block, E. (2016a). Reconsidering the orphan problem: the emergence of male caregivers in Lesotho. *AIDS care*, 28(sup4), 30-40.
- Block, E. (2016b). The AIDS House: Orphan Care and the Changing Household in Lesotho. *Anthropological Quarterly*, 89(1), 151-180.
- Bock, J., & Johnson, S. E. (2008). Grandmothers' productivity and the HIV/AIDS pandemic in sub-Saharan Africa. *Journal of Cross-Cultural Gerontology*, 23(2), 131-145.
- Buch, E. D. (2015). Anthropology of Aging and Care. *Annual Review of Anthropology*, 44, 277-293.
- Burman, S. (1996). Intergenerational Family Care: Legacy of the Past, Implications for the Future. *Journal of Southern African Studies*, 22(4), 585-598.
- Carsten, J. (2013). *Care Between Past and Future: Continuity and Discontinuity in Contemporary Caregiving*. Paper presented at the American Anthropological Association Annual Meeting, Chicago, IL.

- Chimwaza, A. F., & Watkins, S. C. (2004). Giving care to people with symptoms of AIDS in rural sub-Saharan Africa. *AIDS Care, 16*(7), 795-807.
- Collins, D. L., & Leibbrandt, M. (2007). The financial impact of HIV/AIDS on poor households in South Africa. *Aids, 21*, S75-S81.
- Cook, J., Boxer, A., Burke, J., Cohen, M., Weber, K., Shekarloo, P., Mock, L. (2003). Child Care Arrangements of Children Orphaned by HIV/AIDS: The Importance of Grandparents as Kinship Caregivers. *Journal of HIV/AIDS & Social Services, 2*(2), 5-20.
- Dilger, H. (2008). "We Are All Going to Die": Kinship, belonging, and the morality of HIV/AIDS-related illnesses and deaths in rural Tanzania. *Anthropological Quarterly, 81*(1), 207. doi:10.1353/anq.2008.0009
- Drah, B. (2012). Orphans in Sub-Saharan Africa: The Crisis, the Interventions, and the Anthropologist. *Africa Today, 59*(2), 2-21.
- Farmer, P. (1999). *Infections and inequalities: The modern plagues*. Berkeley: University of California Press.
- Foster, G. (2000). The capacity of the extended family safety net for orphans in Africa. *Psychology, Health & Medicine, 5*(1), 55-62.
- Goody, E. (1984). Parental strategies: calculation or sentiment?: fostering practices among West Africans. In H. Medick & D. W. Sabeen (Eds.), *Interest and emotion: essays on the study of family and kinship* (pp. 266-277). Cambridge; New York: Paris: Cambridge University Press; Editions de la Maison des Sciences de l'Homme.
- Graham, N., Gwyther, L., Tiso, T., & Harding, R. (2013). Traditional Healers' Views of the Required Processes for a "Good Death" Among Xhosa Patients Pre-and Post-Death. *Journal of pain and symptom management, 46*(3), 386-394.
- Green, J. W. (2012). *Beyond the good death: The anthropology of modern dying*. Philadelphia: University of Pennsylvania Press.
- Guest, E. (2003). *Children of AIDS: Africa's orphan crisis*. London; Sterling, Va.: Pietermaritzburg, South Africa: Pluto Press; University of Natal Press.
- Hertz, R. (2013). *Death and the right hand* (Vol. 4). Oxon, U.K.: Routledge.
- Howarth, G. (2007). *Death and dying: A sociological introduction*. Cambridge: Polity.
- Johnson, N., Cook, D., Giacomini, M., & Willms, D. (2000). Towards a "Good" Death: End-of-Life Narratives Constructed in An Intensive Care Unit. *Culture, medicine and psychiatry, 24*(3), 275-295.

- Kaufman, S. R., & Morgan, L. M. (2005). The anthropology of the beginnings and ends of life. *Annu.Rev.Anthropol.*, 34, 317-341.
- King, S. V. (2008). Introduction to the journal of cross-cultural gerontology, special issue on aging and social change in Africa. *Journal of Cross-Cultural Gerontology*, 23(2), 107-110.
- Klaits, F. (2010). *Death in a church life: Moral passion during Botswana's time of AIDS*. Berkeley, CA: University of California Press.
- Livingston, J. (2003). Reconfiguring old age: Elderly women and concerns over care in southeastern Botswana. *Medical Anthropology*, 22(3), 205-231.
- Madhavan, S. (2004). Fosterage patterns in the age of AIDS: continuity and change. *Social Science & Medicine*, 58(7), 1443-1454.
- Maloka, T. (1998). Basotho and the Experience of Death, Dying, and Mourning in the South African Mine Compounds, 1890-1940. *Cahiers d'études africaines*, 17-40.
- Mimica, J. (1996). On dying and suffering in Iqwaye existence. *Things as they are: new directions in phenomenological anthropology*, 213-237.
- Niehaus, I. (2007a). Death before Dying: Understanding AIDS Stigma in the South African Lowveld. *Journal of Southern African Studies*, 33(4), 845-860.
- Niehaus, I. (2007b). Death before Dying: Understanding AIDS Stigma in the South African Lowveld*. *Journal of Southern African Studies*, 33(4), 845-860.
- Nyambedha, E. O., Wandibba, S., & Aagaard-Hansen, J. (2003). Changing patterns of orphan care due to the HIV epidemic in western Kenya. *Social Science & Medicine*, 57(2), 301-311.
- Nyesigomwe, L. (2005). Strengthening the Capacity of Grandparents in Providing care to Young Children Affected by HIV/AIDS. *Journal of Intergenerational Relationships*, 4(1), 55-63.
- Palgi, P., & Abramovitch, H. (1984). Death: A cross-cultural perspective. *Annual Review of Anthropology*, 385-417.
- Powell, R. A., Namisango, E., Gikaara, N., Moyo, S., Mwangi-Powell, F. N., Gomes, B., & Harding, R. (2014). Public priorities and preferences for end-of-life care in Namibia. *Journal of pain and symptom management*, 47(3), 620-630.
- Russ, A. J. (2005). Love's labor paid for: gift and commodity at the threshold of death. *Cultural Anthropology*, 20(1), 128-155.

Schatz, E., & Ogunmefun, C. (2007). Caring and contributing: The role of older women in rural South African multi-generational households in the HIV/AIDS era. *World Development*, 35(8), 1390-1403.

Van der Geest, S. (2004). Dying peacefully: considering good death and bad death in Kwahu-Tafo, Ghana. *Social science & medicine*, 58(5), 899-911.

Whyte, S. R., Alber, E., & Geissler, P. W. (2004). Lifetimes intertwined: African grandparents and grandchildren (Vol. 74, pp. 1(5)).

Notes

ⁱ My knowledge of Lesotho is based on two years of fieldwork in the rural mountainous district of Mokhotlong, between 2007 and 2015.