



Food meanings in HIV and AIDS caregiving trajectories: Ritual, optimism and anguish among caregivers in Lesotho

Mokhantšo G. Makoa*

Human Science Research Council, Population Health, Health Systems & Innovation, Cape Town, South Africa

(Received 15 February 2010; final version received 14 September 2010)

The article describes the caregiving responsibility to provide food for chronically ill family members and the meanings attached to food and eating when ill created stress for family caregivers. The results come from a qualitative phenomenological study using in-depth interviews with 21 family caregivers of chronically ill HIV and AIDS patients in one district in Lesotho. Analysis of the interview data showed that the caregivers attached profound meanings to food and feeding care recipients. Their perceptions about food as part of family life and caring, the role of food and eating in curbing disease progression, the link between food and medical efficacy and the link between food and life led to ritualised behaviour around food, and moments of optimism and anguish in caregiving. Patients' behaviour in relation to food was in most instances inconsistent with the caregivers' goals, thus leading this aspect of caregiving to induce stress. Services intended to support home-based caregivers and patients could contribute to the reduction of stress associated with food through suitably tailored food assistance and professional support to caregivers to enhance their competences and understanding of the dynamics of food intake as AIDS progressed.

Keywords: AIDS caregiving; food meanings; eating-related stress; stress proliferation

Background

Lesotho, with an estimated population of 1.8 million in 2006 (World Health Organization [WHO], 2005) and an adult HIV prevalence of 23.2% in 2007 (WHO, 2008), is one of the countries most affected by HIV and AIDS in the world. High AIDS-related morbidity has reduced the capacity of the public healthcare sector to provide services including hospitalisation for chronically ill patients. Generally, chronically ill patients with varying degrees of symptom intensity are cared for by family members who may be supported by volunteers trained by non-governmental organisations and the public healthcare system (Rodlach, 2009).

Unavailability of anti-retrovirals (ARVs) was a dominant element of home-based care in Lesotho until November 2004 when ARVs were introduced in the public healthcare sector. Coverage among those in need of treatment has increased but remains below 50% (Khobotlo et al., 2009). People living with HIV who are not

*Email: mmakoa@hsrc.ac.za

enrolled on the ARV programme depend on a minimum package of care intended to treat opportunistic infections. Consequently, AIDS-related illnesses are common.

Lesotho's high adult morbidity incidence is correlated with widespread food insecurity and household level poverty (Moeti, Mphale, Makoae, & Tango International Consultants, 2002; Mphale, Rwambali, & Makoae, 2002), and inter-household coping mechanisms in rural areas have weakened, thus reducing the resilience of households and their capacity to cope with stressors such as chronic illness (Drimie, 2003; Turner, 2003). Maluti Seventh Adventist Hospital, an institution that pioneered the provision of ARVs and one of the study sites, launched a care and treatment programme that included food security and income generation components for households affected by HIV/AIDS in 2001. In addition, the state and international non-governmental agencies have since 2002 partnered with hospitals to provide households affected by chronic illness and providing home-based care, with food parcels through targeted food assistance. The interventions formed part of the social protection regime intended to protect vulnerable families from hunger, support patients with medical regimens and enhance their well-being. However, these interventions were either inadequate or unsuitable and did not help to reduce distress related to feeding patients.

Conceptual framework

Pearlin, Aneshensel, and Leblanc (1997) use the notion of stress proliferation to explain experiences among AIDS caregivers. Stress proliferation entails the expansion of initial stressors or emergence of stressors in areas that were initially stress-free, thus leading to an accumulation of stressful factors in caregiving. The framework distinguishes primary stressors from secondary stressors. The former entails stressors which emanate from the actual performance of tasks in activities of daily living and include both the objective demands and subjective assessment of the caregivers about their caregiving situation. The latter results from providing care but do not arise directly from performing the caregiving tasks or duties. The caregivers feel overloaded if they encounter hardships in their role and the "chronic and progressive nature of AIDS is a prime mechanism behind the expansion of stressors among AIDS caregivers" (Pearlin et al., 1997, p. 233). This conceptualisation of the difficulties encountered in caregiving recognises that the context of care contributes to caregivers' experiences.

The context of home-based care is important for understanding the meanings caregivers' attach to food and feeding the chronically ill. The dominant perspective on caregiving experiences emphasises the negative impacts of chronic illness on families (Aneshensel, Pearlin, & Schuler, 1993; D'Cruz, 2002; Land & Hudson, 2002; Litt, 2004; Pakenham, Dadds, & Terry, 1995; Tolliver, 2001). Horwitz and Reinhard (1995, p. 139) identify two aspects of caregiving as "caregiver duties" and "caregiver burden." The former are the activities and responsibilities of the caregiver. The latter are the negative outcomes of providing care for chronically ill family members. Zarit, Todd, and Zarit (1986) defined caregiver burden as "the extent to which caregivers perceived their emotional or physical health, social life, and financial status as suffering as a result of caring for their relative" (quoted in Yamamoto and Wallhagen, 1997, p. 164).

Critics emphasise the usefulness of approaching chronic illness neutrally and perceiving adaptation and management of symptoms as part of the lived experience

in illness (Bury, 1991). Prout, Hayes, and Gelder (1999) studied how families managed childhood asthma and found that the “burden” was minimised by suitable adaptive strategies adopted by family members helping them to make sense of the conditions. Specifically, suitable medication was a catalyst in participants’ experiences. Likewise, Berg-Weger, Rubio, and Tebb (2001) studied caregivers of the elderly and suggested that adopting a “strength-based approach” gave insight into the positive aspects of caring. The constructs of “caregiver adjustment,” “competence” and “spiritual connection” highlighted the caregivers’ positive experiences and showed that caregiving could be both rewarding and difficult. Powell-Cope and Brown (1992) and Tolliver (2001) concluded that in addition to the daily stressors – depression and frustration – carers realised social and personal benefits such as empowerment and activism in HIV/AIDS-related activities.

HIV/AIDS caregiving burden in sub-Saharan Africa is compounded by material hardships. Family members experience stress and financial burden as a result of caring for relatives living with HIV/AIDS (Ankrah, 1993; Baylies, 2002; Bindura-Mutangadura, 2000; Chimwaza & Watkins, 2004). As a result of protracted illness, household resources are eroded and families’ capacity to provide care is gradually diminished by illness (Seeley et al., 1993). Uys (2003) emphasises that lack of the essential skills, knowledge and emotional support render caregiving extremely challenging, as caregiving is provided without professional support (Mupedziswa, 1998) for caregivers who assist patients with their expanding care needs. Families provide care under difficult circumstances due to protracted illness, severe symptoms, absence of ARVs and lack of information regarding HIV diagnosis (Makoae & Jubber, 2008).

There is paucity of literature on how family caregivers experience changes in patients’ eating-related behaviours and the associated meanings. Studies indicate difficulties with feeding patients in hospital settings (Holmes, 1999), elderly care (Weetch, 2001) and terminal cancer care (Inui, 2002; Strasser, Binswanger, Cerny, & Kesselring, 2007). Understanding the stress associated with food and feeding AIDS patients in informal care settings is especially crucial in the context of food scarcity, a direct contrary of the developed world characterised by food abundance and variety (Holmes, 1999; Rozin, 2005). The social and symbolic meanings attached to food and how these affect caregiver well-being need exploration. Particularly when the convention regarding the efficacy of medicines is untenable, the significance of food in influencing the direction of illness may be amplified. Therefore, caregiving contexts in which food is insufficient or there is poor food intake by patients are bound to influence caregivers’ experiences profoundly.

The significance of this article lies in the centrality of food, feeding and eating in the care of the chronically ill in resource-poor settings. Food as nutrition is not only as important, if not more important than medicine, but its associated social, moral, cultural and spiritual meanings and symbolism contribute to the immaterial forces that sustain and heal the ill and reward those who care for them. The analysis shows that the caregivers’ experiences were due to the care recipients’ food-related behaviour and their relationship with caregiving goals.

Methods

Study design and sample

This article analyses part of the findings from a qualitative study conducted in Lesotho between 2004 and 2006 among HIV/AIDS family caregivers. The study

examined caregiving experiences of family members in home-based care. Twenty-one study participants were selected purposively with the help of the health workers responsible for HIV/AIDS counselling and testing in two hospitals, one state owned and another managed by a faith-based organisation – both located in Berea District. They included mainly current caregivers and three ex-caregivers, who had exited caregiving following the patients' death. The majority of the caregivers were females ($n = 16$ females and five males). Their ages were 23 to 85 years and they cared mainly for youths and adults (see Makoae, 2009) for detailed description of the methodology. Caregiver–care recipients relationships reflected the complexity of the African family structure: parent–child, grandmother, siblings, aunt/uncle and in-laws. However, only three of the caregivers were informed about the patients' HIV-positive status while most only suspected the patients had AIDS-related illnesses.

Data collection

The phenomenological method (Cresswell, 1998; Moustakas, 1994) was used to conduct face-to-face in-depth interviews that generated caregivers' perspectives about their experiences. Family caregivers were asked to describe what providing care for the patients entailed and what their experiences with the role were. The caregivers described in detail their experiences regarding various aspects of caregiving. Feeding the care recipient and the experiences and meanings linked to this activity were among the matters explored in the interviews. Each interview lasted between 1.5 and three hours, and spread over two–three days. Interviews were audio-recorded with the permission of the caregivers and took place at a caregiver's or patient's home and sometimes in the presence of the patient. The interviews were transcribed verbatim and translated from Sesotho into English by the researcher.

Data analysis

The transcripts were read to gain general understanding of the descriptions of providing food and feeding patients. This process produced general or universal meanings of the caregivers' actions and experiences (Moustakas, 1994, p. 13). The transcripts were coded using themes that emerged from the interviews. This process led to identification of sub-themes on how food and feeding the patients were experienced. Detailed descriptions of the experiences were retained to give context. The themes were the meanings attached to providing food to patients: emotions related to patients' food intake patterns; and sustaining hope by feeding patients.

Findings

The analysis indicates that food was integral to the caregiving role and had several overlapping meanings including being part of family routines and rituals; its moral dimension as an expression of care; its association with maintaining life and showing the will to live on the part of the caregivers and patients, respectively. The emotions that arose showed the link between the caregivers' expression of a caring attitude by providing food and the care recipients' actions which sometimes deviated from this norm due to severe illness and suffering. Mainly, the caregivers expected the care recipients to receive food and their bodies to respond to care by gaining weight and improving in appearance.

Perceived significance of food and eating in caregiving

Caregiving included thwarting conditions which were considered to accelerate the progression of disease and reinforce its effects on the body including the physical appearance of the patients. The most significant conditions were loss of weight and energy which the caregivers feared because these conditions eventually incapacitated the patients. They tried to counteract this situation by providing food and ensuring that the care recipients ate.

Maintaining rituals

First, providing food to the ill family members was the essence of caregiving and part of the caregivers' efforts to maintain normality. Its significance was highlighted in different ways including the fact that the beginning of a new day was marked by serving patients food and that serving food maintained them part of meal routines.

I would wake up early in the morning and prepare her soft porridge and give her medication ... I then cooked food so that we could have lunch. (Mother-in-law)

We struggle when it is mealtime because it does not mean that I will just leave her like that when all the people in the house are eating. (Daughter)

Second, the routine of serving food daily and the strategies which the caregivers used to ensure the patients' food intake indicated that food was central to the caregiving activity and the caregivers did not want their other roles to interfere with patients' eating routines. They ensured that the patients who were relatively independent had food even when they were not with them.

If I go away, I always make sure that I leave food where he can ask even a visitor who walks in ... every time when I leave I make provision for food ... (Son)

When he is at his own place [alone] I take large servings of food in the morning and he serve himself during the day. (Sister-in-law1)

Strategies for ensuring food intake

Sustaining the patients' food intake was vital, and the caregivers used various strategies that included ensuring food availability, monitoring, encouraging, persuading, coercing as well as feeding the patients. The caregivers were vigilant of how the patients ate food; in some cases they requested other family members as well to observe the patients. One said:

I have also taught these other children to watch her closely especially with food and if she eats less, they encourage her to have more ... I watch her carefully. (Father1)

Sometimes the caregivers were stricter and compelled the care recipients to take food because they were anxious they would die or feared they would relapse, and caregiving challenges would intensify or recur. Other participants coerced the patients.

I told her strongly that we don't have a pig here she should eat and finish her food ... I did not want her to lose energy so when she did not eat well I got worried. (Aunt)

Another caregiver said:

... She refused to eat saying that food was not tasty ... I would sit next to her with a stick ... thrash her lightly ... her baby died because her mother was not lactating well. I'd tried, persuaded her and fed her. (Father2)

On three occasions, the caregivers were observed feeding patients who could not open their mouths or swallow the food. One of the caregivers expressed her dilemma as she continued to feed a terminally ill patient – she could not move her limbs and her face was covered with a net to keep flies away from her eyes and mouth. She said:

Now she cannot eat, she cannot swallow anything. She is fed this soft porridge, yet it is very difficult ... (Mother1)

Emotions related to food intake

The caregivers' emotions associated with the patients' eating patterns indicated how food and feeding the patients were intricately linked to "the caregivers' identity" as sustainers and understandings of how food benefited the ill by restoring energy and halting disease progression. At the same time the caregivers benefited by experiencing positive emotions when the patients enjoyed food. The emotions included hope and satisfaction when the patients adhered to eating norms and negative thoughts when they deviated.

Optimism: Feeling good and hopeful

When the care recipients consumed food, the caregivers felt encouraged and their fear that the health condition of the care recipients would deteriorate subsided. One stated:

He is now able to eat ... a lot and this gives me courage that he will be better ... [his] body is weak but I still believe that a person will not recover instantly. (Father3)

Some caregivers compared the times when the patients ate well and when they did not indicating that the former brought positive outlook in caregiving while the latter was associated with stress. Comments in this regard were:

... when he listens it encouraged me that he would be better even if he might not be as healthy as he used to be. (Sister-in-law1)

One thing that made me happy was when I saw her eating well ... she gave me courage because she showed me that she was responsible. (Aunt)

Another one said:

Now she reminds me about food and I'm happy ... it is good because this virus should not get a chance to destroy her body, it makes me feel hopeful. (Sibling)

Positive emotions were neither common nor persisting in caregiving as they were soon replaced by more enduring negative experiences as shown below.

Anguish, guilt and hopelessness

When the patients were reluctant or unable to eat, the caregivers experienced stress regardless of the factors responsible for the patients' behaviour because it contradicted caregiving values and goals. Concerns with patients' food preferences, regaining weight and vitality, enhancing the efficacy of medicines and preventing death indicated the anxiety which the caregivers experienced with the patients' changing health situation and their own limitations to curb intractable AIDS symptoms by simple techniques including food.

Food preferences and guilt

Some of the caregivers experienced guilt when the patients did not eat food. They believed food aversion was exacerbated by lack of choice in the food packages received from the intervention schemes and the inability of the family to meet the patients' food preferences due to fluctuating appetite. For example, caregivers stated:

She does not like the porridge that we make with the flour that we get from the (NGO) because she says it has an unpleasant smell. (Daughter)

It is painful because sometimes a patient develops these crazy taste buds ... he spent days eating a little, he wanted meat ... (Grandmother)

Not eating threatened weight gain and vitality

Severe symptoms such as vomiting, difficult breathing and coughing that interfered with their ability to eat were stressful because the caregivers were concerned that decline in food intake led to severe weight loss and incapacitation. Some stated:

She has this thing that makes her breathe with difficulty when she is in pain – she cannot swallow medicine or food ... (Sibling)

She had this relentless cough which led to her vomiting ... She did not like anything going into her mouth ... (Mother3)

But the caregivers would try different strategy to ensure continuity. Some initially believed that they could control the situation by ensuring food and medicines intake. For example, where severe weight loss was associated with neglect, a caregiver believed they could improve the situation with food:

... she was weakened by starvation because I think they would just serve her and if she did not eat it did not bother them ... I then fed her and she became stronger ... (Aunt)

The caregivers were frustrated when the patients did not eat, finish their servings or maintained eating routines. Living arrangements interfered with the need to monitor the patients eating patterns. One caregiver indicated that the irregular eating habits contradicted her own values. She expressed her anxiety:

Sometimes I take food there but he is less motivated to eat and he just leaves the food the whole day ... misses midday meals and dose. It makes me feel bad ... now he has deteriorated. (Sister-in-law1)

Another stated:

He would not eat anything ... he would pick a little. That distressed me because I was telling him that he should eat to regain his strength. (Uncle2)

Without eating, medicines would not work

The caregivers perceived food and medicines as complementary; eating food enhanced the efficacy of medication and maintaining this balance would eventually ameliorate the patients' symptoms and restore health. Most caregivers emphasised the interplay between food, medicine and the disease, saying:

I talk to him because you see there is no way we can expect these medicines to work if the body is not receiving food. (Spouse2)

I tell him that if he does not eat and does not take his medication, he won't become better and he will spend a long time sleeping or laying in bed. (Sister-in-law1)

Not eating: Death harbinger

The patients' anti-food behaviour intensified the caregivers' thoughts about death. Frustration emerged when the patients' attitude towards food did not seem to reinforce efforts against the perceived "enemy" – death. Some caregivers related how the onset of this behaviour distressed them as sometimes it was unexpected or confirmed their fears. The psychosocial consequences of patients stopping to eat on the caregivers and the latter's desperate efforts to encourage food intake are highlighted below.

... his appetite has changed. I thought he didn't eat because of the sore throat but even soft food ... I think it is because his mouth has this white lining but I clean it ... he makes me think hard ... (Spouse2)

... if someone doesn't eat, medicines don't work, and you are immediately sure that this person is not going to live ... (Sister-in-law3)

Caregivers who had already experienced death recalled poor food intake as one of the signals that marked the onset of their mourning.

When she died, she was completely dry because she had stopped eating for many days. She could not swallow anything ... You could sympathize ... (Mother1)

A spouse experienced this behaviour early in her caregiving role. She stated:

He was so worried about [HIV] that he even stopped eating ... after we returned from the hospital ... his condition just declined. (Spouse1)

Another caregiver was depressed when the patient suddenly refused to take food and medication after she realised that medication did not make her feel better. It was common for patients to surrender when the symptoms persisted despite their adherence to medication, causing the caregivers despair. A caregiver described the pain that he suffered when the patient stopped eating:

I wished I could hold her life but she was in pain and I remember I felt very disturbed because she stopped eating. I said: please try to eat ... she said "I am already finished" ... it was over. (Spouse1)

The association of food with life and the perception that patients who ate well promised to survive meant that patients' death under what appeared normal circumstances was inexplicable yet equally distressing. One caregiver said:

Her eating was encouraging ... her appetite improved ... and that encouraged me ... She spent the two months after she was diagnosed doing very well, she was alive ... She was doing well. (Mother-in-law)

Discussion

Food and feeding chronically ill patients are integral to the caregiving role and the emotions related to feeding patients highlight how different caregiving contexts as determined by the availability of preferred food, the severity of the symptoms, caregiver competences and perceived bodily changes influence caregiving experiences over time. Initially most caregivers managed to integrate the responsibility to feed the patients within their role but the activities expanded as the disease progressed highlighting the elements of the stress proliferation framework (Pearlin et al., 1997).

On the one hand, when the care recipients ate food according to the caregivers' expectations the caregivers experienced less anguish and hope but such situations were rare while negative experiences were more common. The caregivers felt encouraged when the cared-for ate well because in their view the behaviour gave hope for recovery. The finding illustrates first, that availability of suitable food in home-based care could assist the caregivers to adapt to caregiving. Availability of appropriate medicines was found to reduce negative experiences among families managing childhood asthma (Prout et al., 1999). Ability to eat as expected gave courage suggesting that poignant experiences in caregiving were not inevitable (Bury, 1991). Second, it suggests that care should be conceptualised and practised as a two-way relational process involving reciprocity and interdependence between caregivers and the cared-for (Lingler, Sherwood, Crighton, Song, & Happ, 2008; Noddings, 1984; Tronto, 1993). The caregivers experienced less stress because they perceived the care recipients as responding to their caregiving efforts. These experiences further showed that care entailed emotions and interdependence between the caregivers and the care recipients – "feelings, responsibility, responsive action, and relationship" (Duffy, 2005, p. 69). Unfortunately, when the patients ate well it gave false hope leading to disappointment when they suddenly deteriorated despite such efforts. Mok, Chan, Chan, and Yeung (2003) described family caregivers' experiences when caring for terminally ill relatives as characterised by intense emotions of hope and hopelessness, guilt, fear and regret.

On the other hand, both objective symptoms and the behaviour of patients that impeded food intake produced poignant experiences – anxiety, anger and pessimism. Observing the undesirable changes in the patients' food intake patterns was stressful. Stress accumulated because of the need to reconsider the food normally served, the concomitant need to help the patients by feeding them and their loss of weight. Food intake-related problems spiralled as the AIDS disease progressed. Studies explain this situation in terms of dwindling household resources among affected families

(Bindura-Mutangadura, 2000; Chimwaza & Watkins, 2004). This explains why nutrition is integral to most HIV/AIDS intervention (Strasser, Egge, Huddle, & Greenaway, 2005).

However, this study points to another dimension of feeding AIDS patients, namely the factors that contribute to caregiver stress in this role. The symptoms that inhibited normal eating such as mouth infections, nausea and appetite loss or the long-term effects of the disease that required the caregivers to pay attention to feeding the patients – extreme weight loss and loss of independence – contributed significantly to the “proliferation of stressors” (Pearlin et al., 1997) among the caregivers. Pearlin and colleagues’ notion that stressors can expand is illustrated by the changes in the caregiving demands and the emotional consequences of some of the eating-related behaviour. Mundane concerns about ensuring that food was prepared and served to the ill – “primary stressors” – intensified. The caregivers became burdened by the need to feed, persuade or coerce the patients to take food in order to curb weight loss and imminent death.

Ameliorating weight loss with food was an explicit caregiving goal and the caregivers expected the care recipients’ food-related behaviour to complement this goal. Sometimes the patients were unable or resisted to eat. The concern was that weight loss contributed to increased caregiving workload as the patients lost dependence over time. While the caregivers could relate loss of appetite to severe symptoms and food scarcity in households their strong perception about the link between food and life led to them experiencing intense emotions when the patients did not eat. The patients refused food when they were in extreme pain and this occurred at different stages of the caregiving trajectories. When the changes occurred, the caregivers become the patients’ sustainers and encourage them to continue to eat even though they may not think the patients suffered due to intake cessation (Meares, 1997). In this study, the caregivers actually associated patients’ deterioration with poor food intake. Strasser et al. (2007) indicate that nutritional interventions are introduced in cancer care to alleviate the associated with patients’ food intake cessation. They argue that the emotions arise because eating and enjoying food are linked to life, care and nurturing while poor appetite is associated with dying. They indicate that the caregiver distress when terminally ill patients’ cannot eat is largely an existential concern because in the first place, there is a common understanding that not eating and inexplicable weight loss signal death and therefore these conditions create anxiety in caregiving. Hence, the caregivers endeavoured to maintain orderliness and continued to assist critically ill patients ingest food.

Even when feeding the patients seemed worthless because the patients could not swallow it, the ritual of serving food continued. The symbolic significance of feeding terminally ill patients and the concern about it may surpass reason (McInerney, 1992). The caregivers persuaded or even forced the care recipients to eat. The care recipients who ate appropriately raised hope about recovery. However, how bodies actually responded was beyond the caregivers’ control. Commenting on the emotional impact of feeding terminally ill patients, McInerney (1992) illustrated that family members noted otherwise insignificant physical changes such as weight gain by patients.

The cultural meaning of food and eating are important. Moss, Moss, Kilbride, and Rubinstein (2007) indicate that food and eating play important functions in family life. In this way, the caregivers’ efforts to ensure that the patients ate should

be viewed as a ritual through which they expressed their cultural dispositions (Turner, 1969). Serving food to people, including strangers, is central to Basotho culture and people's morality and compassion is questioned when they show stingy tendencies.

On the basis of the findings and arguments, it is strongly recommended that services intended to support home-based caregivers and patients, including palliative care programmes, should contribute to the reduction of stress associated with food through suitably tailored food assistance, information and professional support to caregivers to enhance their competences in feeding patients and eating in caregiving. Carers should also be made aware that in some instances caregiving activities will prolong life, even be linked to recovery and restored health, but in some cases, they will not have the expected positive effect.

There is paucity of research on how AIDS caregivers experience eating-related behaviours of patients. There is need for evidence that can inform home-based care interventions. Caregivers' responses to the patients' food-related behaviour suggest that home-based care interventions that are based on the understanding of how patients influence the quality of their care can contribute to caregivers' well-being. Caregiver-patient counselling services are necessary and these should be supported through home-based care monitoring. Evidence-based patients' feeding programmes should be integrated into national responses to HIV and AIDS.

Acknowledgements

I thank the caregivers and their relatives, the healthcare workers who assisted with access to the caregivers and the WFK Kellogg Foundation (USA) and the Academy for Educational Development for funding the study. My gratitude goes to Professor Ken Jubber, University of Cape Town, for his comments on the earlier versions of the manuscript.

References

- Aneshensel, C.S., Pearlin, L.I., & Schuler, R.H. (1993). Stress, role captivity, and the cessation of caregiving. *Journal of Health and Social Behaviour*, 34(1), 54–70.
- Ankrah, E.M. (1993). The impact of HIV/AIDS on the family and other significant relationships: The African clan revisited. *AIDS Care*, 5(1), 5–22.
- Baylies, C. (2002). The impact of AIDS on rural households in Africa: A shock like any other? *Development and Change*, 33, 611–632.
- Berg-Weger, M., Rubio, D.G., & Tebb, S.S. (2001). Strength-based practice with family caregivers of the chronically ill: Qualitative insights. *Families in Society*, 82(3), 263–272.
- Bindura-Mutangadura, G. (2000). HIV/AIDS, poverty, and elderly women in urban Zimbabwe. *Southern African Feminist Review*, 4(2), 93–105.
- Bury, M. (1991). The sociology of chronic illness: A review of research and prospects. *Sociology of Health and Illness*, 13, 451–468.
- 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.
- Cresswell, J.W. (1998). *Qualitative inquiry and research design: Choosing among five traditions*. Thousand Oaks, CA: Sage.
- D'Cruz, P. (2002). Engulfing darkness: The impact of HIV/AIDS on the family. *Families in Society*, 83(4), 416–430.
- Drimie, S. (2003). HIV/Aids and land: Case studies from Kenya, Lesotho and South Africa. *Development Southern Africa*, 20(5), 647–658.
- Duffy, M. (2005). Reproducing labour inequalities: Challenges for feminists conceptualising care at the intersections of gender, race and class. *Gender and Society*, 19(1), 66–82.
- Holmes, S. (1999). Nutrition: A necessary adjunct to hospital care? *The Journal of the Royal Society for the Promotion of Health*, 119(3), 175–179.

- Horwitz, A.V., & Reinhard, S.C. (1995). Ethnic differences in caregiving duties and burdens among parents and siblings of persons with severe mental illnesses. *Journal of Health and Social Behaviour*, 36(138), 150.
- Inui, A. (2002). Cancer Anorexia-Cachexia Syndrome: Current issues in research and management. *CA Cancer Journal of Clinicians*, 52, 72–91.
- Khobotlo, M., Tshehlo, R., Nkonyana, J., Ramoseme, M., Khobotle, M., Chitoshia, A., ... Fraser, N. (2009). *Lesotho HIV prevention response and modes of transmission analysis*. Maseru: Lesotho National AIDS Commission/UNAIDS.
- Land, H., & Hudson, S. (2002). HIV serostatus and factors related to physical and mental well-being in Latina family AIDS caregivers. *Social Science and Medicine*, 54, 147–159.
- Lingler, J.H., Sherwood, P.R., Crighton, M.H., Song, M.K., & Happ, M.B. (2008). Conceptual challenges in the study of caregiver-care recipient relationships. *Nursing Research*, 55(5), 367–372.
- Litt, J. (2004). Women's care work in low-income households: The special case of children with attention deficit hyperactivity disorder. *Gender and Society*, 18(5), 625–644.
- Makoe, M.G. (2009). The phenomenology of bodily care: Caregivers' experiences with AIDS patients before antiretroviral therapies in Lesotho. *African Journal of AIDS Research*, 8(1), 17–27.
- Makoe, M.G., & Jubber, K. (2008). Confidentiality or continuity? Family caregivers' experiences with care for HIV/AIDS patients in home-based care in Lesotho. *Journal of Social Aspects of HIV/AIDS*, 5(1), 36–46.
- McInerney, F. (1992). Provision of food and fluids in terminal care: A sociological analysis. *Social Science & Medicine*, 34(11), 1271–1276.
- Meares, C.J. (1997). Primary caregiver perceptions of intake cessation in patients who are terminally ill. *Oncology Nursing Forum*, 24(10), 1751–1757.
- Moeti, L., Mphale, M., Makoe, M., Tango International Consultants (2002). *Lesotho emergency food security assessment report*. Maseru: Lesotho Vulnerability Assessment Committee & SADC FANR Vulnerability Committee.
- Mok, E., Chan, F., Chan, V., & Yeung, E. (2003). Family experience caring for terminally ill patients with cancer in Hong Kong. *Cancer Nursing*, 26(4), 267–275.
- Moss, S.Z., Moss, M.S., Kilbride, J.E., & Rubinstein, R.L. (2007). Frail men's perspectives on food and eating. *Journal of Aging Studies*, 21(4), 314–324.
- Moustakas, C. (1994). *Phenomenological research methods*. Thousand Oaks, CA: Sage.
- Mphale, M., Rwambali, E.G., & Makoe, M.G. (2002). *HIV/Aids and its impacts on land tenure and livelihoods in Lesotho*. Unpublished report prepared for the Southern African Regional Office of the Food and Agriculture Organisation (FAO) of the United Nations. Retrieved from <http://www.sarpn.org.za>
- Mupedziswa, R. (1998). AIDS in Africa: The social work response. *Journal of Social Development in Africa*, 123–144.
- Noddings, N. (1984). *Caring: A feminine approach to ethics and moral education*. Berkeley: University of California Press.
- Pakenham, K.I., Dadds, M.R., & Terry, D.J. (1995). Carers' burden and adjustment to HIV. *AIDS Care*, 7(2), 189–203.
- Pearlin, L.I., Aneshensel, C.S., & LeBlanc, A.J. (1997). The forms and mechanisms of stress proliferation: The case of AIDS caregivers. *Journal of Health and Social Behaviour*, 38(3), 223–236.
- Powell-Cope, G.M., & Brown, M.A. (1992). Going public as an AIDS family caregiver. *Social Science and Medicine*, 34, 571–580.
- Prout, A., Hayes, L., & Gelder, L. (1999). Medicines and the maintenance of ordinariness in the household management of childhood asthma. *Sociology of Health & Illness*, 21(2), 137–162.
- Rodlach, A. (2009). Home-based care for people living with AIDS in Zimbabwe: Voluntary caregivers' motivations and concerns. *African Journal of AIDS Research*, 8(4), 423–431.
- Rozin, P. (2005). The meaning of food in our lives: A cross-cultural perspective on eating and well-being. *Journal of Nutrition Education & Behavior*, 37(Suppl. 2), S107–S112.
- Seeley, J., Kajura, E., Bachengana, C., Okongo, M., Wagner, U., & Mulder, D. (1993). The extended family and support for people with AIDS in a rural population in south west Uganda: A safety net with holes? *AIDS Care*, 5, 117–122.

- Strasser, F., Binswanger, J., Cerny, T., & Kesselring, A. (2007). Fighting a losing battle: Eating-related distress of men with advanced cancer and their female partners. A mixed-methods study. *Palliative Medicine*, 21, 129–137. Retrieved from <http://pmj.sagepub.com/cgi/content/abstract/21/2/129>
- Strasser, S., Egge, K., Huddle, J., & Greenaway, K. (2005). *Measuring the effect of targeted food assistance on beneficiaries with chronic illness: Lessons learned from the literature and the field*. Paper presented at the International Conference on HIV/AIDS and Food and Nutrition Security, International Food Policy Research Institute, Durban, South Africa. Retrieved from <http://www.c-safe.org/downloads/TFA's%20Impact%20on%20Beneficiaries%20with%20Chronic%20Illness.pdf>.
- Tolliver, D.E. (2001). African American female caregivers of family members living with HIV/AIDS. *Families in Society*, 82(2), 145–156.
- Tronto, J.C. (1993). *Moral boundaries: A political argument for an ethic of care*. New York: Routledge.
- Turner, S. (2003). *The Southern African food crisis: Lesotho literature review*. CARE-SA Lesotho LRAP Discussion paper No. 1. Maseru: CARE-SA-Lesotho.
- Turner, V. (1969). *The ritual process*. London: Routledge & Kegan Paul.
- Uys, L. (2003). A model for home-based care. In L. Uys & S. Cameron (Eds.), *Home-based HIV/AIDS care* (pp. 3–15). Cape Town: Oxford University Press.
- Weetch, R. (2001). Feeding problems in elderly patients. *Nursing Times*, 97(16), 60–63.
- WHO. (2005). *Summary country profile for HIV/AIDS treatment scale-up*. Geneva: World Health Organisation. Retrieved from www.who.int/hiv/HIVCP_LSO.pdf
- WHO. (2008). *Towards universal access: Scaling up priority HIV/AIDS interventions in the health sector*. Progress Report. Geneva: WHO.
- Yamamoto, N., & Wallhagen, M.I. (1997). The continuation of family caregiving in Japan. *Journal of Health and Social Behaviour*, 38, 164–176.