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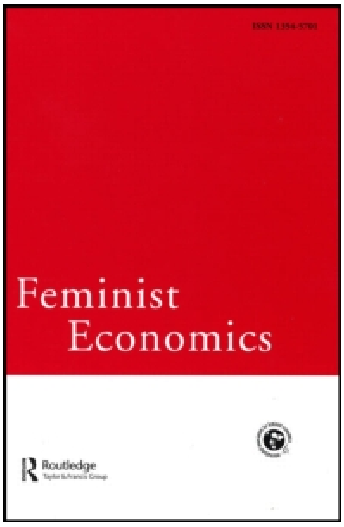

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Unpaid HIV/AIDS Care in Southern Africa: Forms, Context, and Implications

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UNPAID HIV/AIDS CARE IN SOUTHERN AFRICA: FORMS, CONTEXT, AND IMPLICATIONS

Olagoke Akintola

ABSTRACT

Across southern Africa, policy-makers are promoting home-based care for HIV/AIDS patients as a cheaper alternative to hospital care. However, cost studies have not sufficiently considered the costs and benefits to all stakeholders in home-based care.[1] Drawing on existing literature, this study shows that available data are grossly inadequate for a comprehensive assessment of the cost-effectiveness of home-based care. Previous studies have largely ignored many of the costs associated with home-based care, which is currently borne by unpaid caregivers – predominantly women – as well as the value of their unpaid labor. This study questions the assumption that home-based care is cheaper than hospital care and the wisdom of enacting home-based care policies. This study argues that conclusions about the cheaper form of care can be drawn only by assessing all of the costs, benefits, and utility derived by all stakeholders in home-based care.

KEYWORDS

Care cost, unpaid care, home-based care, PLWHA, caregiving, HIV/AIDS

JEL Codes: H31, I18, J17

INTRODUCTION

Across southern Africa, the home is fast replacing hospitals as the primary place of care for HIV/AIDS patients (Elsbeth Robson 2000; Lucy Steinitz 2003; Leana Uys 2003; Olagoke Akintola 2004a). Countries such as Zimbabwe, Malawi, Botswana, Swaziland, Tanzania, Mozambique, Zambia, South Africa, Namibia, Lesotho, and the Democratic Republic of Congo are promoting home-based care for people living with HIV/AIDS (PLWHA)[2] (Robson 2000; South African Department of Health 2001; Steinitz 2003; Zimbabwean Ministry of Health and Child Welfare 2004).[3] The implementation of home-based care in these countries draws heavily on the principles of community participation in primary healthcare. The World Health Organization (WHO) has long endorsed such participation as a means by which communities may take part in decisions on health

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issues that affect them and as a key component of achieving health for all (World Health Organization [WHO] and United Nations Children's Fund [UNICEF] 1978; David J. Zakus 1998). Although home care policies are applied to people living with a range of diseases worldwide (South African Department of Health 2001; WHO 2002), home-based care is almost always synonymous with care for PLWHA in southern Africa for two reasons. First, the primary motivation for drafting these policies has been the need to reduce the burden of HIV/AIDS on public hospitals and reduce the cost of hospital care. A common aim of the home-based care policies adopted in the southern African region is to reduce the length of time that patients stay in hospitals. The policy requires public health facilities to discharge patients early to be cared for at home by family and community members. The primary purpose is to free up bed space for people with other illnesses and reduce the cost to public health institutions.[4] Second, an overwhelming majority of the patients who benefit from home care in many sub-Saharan African countries are PLWHA.[5] As noted above, one major impetus for the shift to home-based care in southern Africa is to reduce the costs associated with hospital care. In this paper I question the assumption that home-based care is cost-effective compared with hospital care. While there are studies that analyze the cost-effectiveness of home-based versus hospital care, these studies do not account for all of the costs imposed on family and community members who provide home-based care, including the value of their unpaid labor.[6] I argue that in order to ascertain the true cost of home-based care there is a need for a comprehensive assessment of costs incurred by all stakeholders in home-based care. A comprehensive assessment of the cost of home-based care requires insights into (1) who home-based caregivers are; (2) what services home-based caregivers provide; (3) what motivates people to become home-based caregivers; and (4) what the implications of home-based care are for caregivers.

This paper reviews the available evidence on home-based care for PLWHA in countries in the Southern African Development Community to provide insights into these questions.[7] The review includes a wide range of published and unpublished documents produced on home-based care in most of the countries in southern Africa (see Appendix).[8] As Appendix 1 shows, most of the literature is retrieved from South Africa, followed by Botswana, Zambia, Tanzania, and Zimbabwe. Only limited literature is available for Malawi, Namibia, Mozambique, Swaziland, and the Democratic Republic of Congo, and only one report was found for Lesotho. I did not find any data for Mauritius, Madagascar, and Angola.[9]

Although feminist economists have written extensively about caring labor, little is to be found on caregiving for PLWHA. Susan Himmelweit (1999), Nancy Folbre and Julie Nelson (2000), and others have noted that caring has two dimensions: the motivation of caring and the actual activity of providing physical and emotional care. While the provision of care for PLWHA has these two dimensions, the characteristics of the disease make both the motivation for caring and the activity of caring a unique experience. The serious stigma surrounding HIV/AIDS compels affected families to provide care in secrecy. PLWHA usually have less hope for complete recovery or cure than patients suffering from most other illnesses.[10] Also, the care required for PLWHA is particularly demanding and strenuous and, in the context of southern Africa, is often carried out without running water, electricity, or indoor toilets (Malcolm Steinberg, Saul Johnson, Gill Schierhout, and David Ndegwa 2002; Angela Chimwaza and Susan Watkins 2004). The particularities of caregiving for PLWHA in southern Africa could lead to new insights into the economics of caregiving.

WHO ARE HOME-BASED CAREGIVERS?

The question of who provides care to PLWHA has not been explored in detail, yet this information is critical for identifying those who are most burdened by caregiving. Across the southern African region, the main or primary caregivers to PLWHA are usually family members and thus referred to as family caregivers (Petri Blinkhoff, Esaya Bukanga, Brigitte Syamalevwe, and Glen Williams 2001: 17; Olagoke Akintola 2006a: 239).[11] Secondary caregivers are family or community members who provide support or respite to the primary caregivers, while community members who volunteer to be trained by home-based care organizations are known as volunteer caregivers (Blinkhoff et al. 2001: 17; Akintola 2006a: 239).[12] I discuss the role of volunteer caregivers and their demographics in a subsequent section.

The demographic profile of family caregivers reported below may not represent the true demographic profile for three reasons. First, most of the studies on caregiving in southern Africa make use of qualitative methods and rarely collect detailed socio-demographic information. Second, these studies rely on very small sample sizes, and third, participants are not randomly selected. Samples are sometimes drawn using the help of home-based care programs and often exclude patients who are not registered with home-based care organizations. This sampling technique has the potential to bias findings. Therefore, the demographic profile derived from these studies cannot necessarily be considered representative of all caregivers. The profile may at best reflect the socio-demographic characteristics of individuals who are registered with home-based care organizations. The paucity of detailed unbiased data on the demographic profile of caregivers makes it difficult to identify the characteristics of the very people most burdened by caregiving and to advocate for policy that mitigates the burden of care on these groups.

Gender of family caregivers

There is increasing consensus in the literature and among home-based care organizations and gender activists that most of those who serve as primary and secondary providers of care for PLWHA are women (Michelle Russel and Helen Schneider 2000; Noeleen Heyzer 2001; Tony Barnett and Alan Whiteside 2002; Joint United Nations Programme on HIV/AIDS [UNAIDS] 2004). In a qualitative study conducted in three townships in the Western Cape province of South Africa, forty-three of the forty-five people caring for a family member with HIV/AIDS were women (Phyllis Orner 2006). A qualitative study on Malawi reported similar results where all fifteen of the study participants were women (Chimwaza and Watkins 2004) and in Botswana where thirty-two of thirty-five caregivers studied were women (Elizabeth Lindsey, Miriam Hirschfeld, and Sheila Tlou 2003). In a non-representative sample from four provinces in South Africa, 68 percent of caregivers were women or girls (Steinberg et al. 2002). Even though recent research has shown that the impact of HIV/AIDS is beginning to challenge traditional stereotypes about men and women's work (Soori Nnko, Betty Chiduo, Flora Wilson, Wences Msuya, and Gabriel Mwaluko 2000; UNAIDS 2000), qualitative studies conducted across the southern African region point to a general reluctance of men to provide care in the home because caring is not seen as conforming with the traditional roles of men as breadwinners and women as homemakers and nurturers (Nnko et al. 2000; Olagoke Akintola 2005a, 2006a; Rick Homan, Catherine Searle, Eka Esu-Williams, Mark Aguirre, Sibongile Mafata, Farshid Meidany, Corrie Osthuizen, and Liz Towel 2005a).

Quantitative studies would provide a better insight into the proportion of men and women providing care than qualitative studies, but there are very few quantitative surveys focusing specifically on caregiving within the context of HIV/AIDS in southern Africa. One exception is a survey of children living with HIV/AIDS drawn from different home-based care organizations in Blantyre, Malawi. This study shows that 94 percent of caregivers were women (E. W. Zimba and Patricia A. McInerney 2001). Another useful quantitative survey conducted in 2004, which drew caregivers purposively from four home-based care organizations across South Africa, found that 78 percent of primary caregivers were women (Homan et al. 2005a). This means that women disproportionately carry the burden of caring for PLWHA with ramifications for their finances and the time that they have available for other productive activities and leisure, as I discuss later.

While some studies have shown that most of the caregivers are mothers, others indicate that sisters predominate. About one-third of primary caregivers in a South African study were mothers while about a quarter were sisters of the patient (Phyllis Orner 2005). A Botswana study found that mothers comprised the highest proportion of primary caregivers while the proportion of grandmothers and daughters was equal (Lindsey, Hirschfeld, and Tlou 2003). Family caregivers also included nieces or cousins of the patients. (Steinberg et al. 2002; Lindsey, Hirschfeld, and Tlou 2003; Chimwaza and Watkins 2004; Walter Kipp, Thomas Nkosi, Lory Laing, and Gian Jhangri 2006; Orner 2006).

Age of family caregivers

In much of the literature on caregiving in other contexts, care providers are able-bodied persons caring for a spouse with Alzheimer's disease, an elderly person, or a child. This is strikingly different from caregiving in the context of HIV/AIDS. Caregivers of PLWHA span a wide range of ages. For example, the ages of primary caregivers in a study conducted in the Eastern Cape province of South Africa ranged from 18–69 years (Orner 2006). A striking feature of HIV/AIDS-related caregiving is the substantial portion of caregivers who are either a generation younger or a generation older than the patients (Lindsey, Hirschfeld, and Tlou 2003; Homan et al. 2005a). Homan et al. (2005a) indicate that 25 percent of caregivers were a generation older than the patients. Nonetheless, the study also found that most of the primary caregivers were in the same generation as the patient and were typically in their reproductive and productive ages. This implies that caring competes with labor force participation for caregivers that are employed or seeking employment as well as those involved in subsistence agriculture and has further implications for the livelihood and food security of the household.[13]

Several studies have documented the existence of child caregivers. Among children below the age of 18, more girls than boys are involved in primary and secondary caregiving (Robson 2000; Lewis Machipisa 2001; Akintola 2004a). Yet, compared to adult caregivers, much less is known about the socio-demographic profile of children serving either as primary or secondary caregivers. As Elsbeth Robson (2004) points out, children who serve as caregivers are usually hidden from public view, and there is a failure on the part of government officials to acknowledge that this category of caregivers exists. Unlike adults, children who become caregivers are usually deliberately excluded by some care organizations from receiving any training from home-based care programs, perhaps to avoid exploiting them as child laborers. Yet, they frequently assume the role of primary caregivers in situations where there is no adult available (Eka Esu-Williams, Joseph Motsepe, Mutale Chomba, and Mangala Chambeshi-Moyo 2002; Akintola 2004a). About 7 percent of primary caregivers in the survey by Steinberg et al. (2002) were under 18 years of age. Homan et al. (2005a) indicates that 18 percent of primary caregivers were less than 26 years old while 4 percent were under 16 years old. Studies on Zimbabwe, Botswana, and South Africa have documented the existence of child primary and secondary caregivers (Robson 2000; Tlou 2000; Olagoke Akintola 2004a, 2006b). The use of children as caregivers has implications for their education and psychological well-being that are discussed in a subsequent section.

Like child caregivers, older people carry a substantial burden of care for PLWHA. (Steinberg et al. 2002; Lindsey, Hirschfeld, and Tlou 2003; HelpAge International 2004, 2005). According to HelpAge International (2004: 11), ‘‘the primary impact of HIV/AIDS on older people in most AIDS affected countries is in their role as caregivers to PLWHAs.’’ Older people comprise a substantial proportion of caregivers of PLWHA especially in households. They typically take on the responsibility of caring for their adult children living with HIV/AIDS as well as grandchildren who may be ill. A recent study found that older people provided care for a quarter of the total number of PLWHA in eight communities in Mozambique (HelpAge International 2005). In a Botswana study, 54 percent of caregivers were 54 years or older (Lindsey, Hirschfeld, and Tlou 2003), and about 23 percent of primary caregivers in South Africa were over 60 years old (Steinberg et al. 2002). Another South African study found that 20 percent of caregivers were over 55 years old. A qualitative study in an urban setting in Tanzania found that many of those in their productive ages who could provide care had died of AIDS leaving older women to be the primary caregivers (Edith Tarimo 2004). Older care providers are vulnerable to poor health and poor socioeconomic outcomes because many of them are frail and suffer from chronic illnesses and are less likely to be earning an income (Lindsey, Hirschfeld, and Tlou 2003; HelpAge International 2004; Tarimo 2004). In sum, these studies show that while most of the caregivers are in the productive age group, a growing proportion of caregivers are older people and children. Home-based care therefore imposes varying magnitudes of financial and opportunity costs on caregivers depending on their age group, affecting the caregiver’s time, schooling, and ability to participate in home and market production. However, the paucity of information on older as well as child care providers obscures the real extent of the impact of home-based care on households and the society at large.

Sources of income

Most primary caregivers have no formal employment. A study on Malawi found that none of the primary caregivers had a formal job (Chimwaza and Watkins 2004). In South Africa, a cohort study comparing HIV/AIDS-affected and unaffected households found that affected households had lower employment rates (Max Bachmann and Frederick Booysen 2003). Homan et al. (2005a) found that over half of the HIV/AIDS-affected households registered with a home-based care organization had no employed person, and 6 percent reported no source of income. In a study of the Eastern Cape province, sixty-three of seventy-two adults were unemployed while others were engaged in informal, episodic, or temporary employment (Michael Samson 2002).

In countries such as Botswana and South Africa where pensions are in place for older people, many households are dependent on government grants and remittances (Frederick Booysen 2002; Samson 2002; Steinberg et al. 2002; Bachmann and Booysen 2003; Lindsey, Hirschfeld, and Tlou 2003; Akintola 2004a). Homan et al. (2005a) found that 34–40 percent of HIV/AIDS-affected family income was in the form of old-age pensions, and other government grants provided between 20–36 percent of household income while paid work provided only 28–36 percent of household income.[14]

Although the literature suggests that HIV/AIDS-affected households are generally poorer than unaffected households (Samson 2002; Bachmann and Booysen 2003) and live in abject poverty, this data is likely to be biased.[15] Many of the studies that provide information on caregiving in southern Africa are conducted in rural and peri-urban and urban slums that are predominantly inhabited by the poor (Lindsey, Hirschfeld, and Tlou 2003; Melissa Edoh 2004; Pathfinder International 2006). In addition, as stated earlier, many of these studies recruited samples with the assistance of care organizations, and it is likely that those who register to receive help from care organizations are those who are poor, have less access to formal and informal sources of support, and are unable to pay for private home-care services.[16] (See Kristian Hansen, Godfrey Woelk, Helen Jackson, Russell Kerkhoven, Norah Manjonjori, Patricia Maramba, Jane Mutambirwa, Ellen Ndimande, and E. Vera 1998; Blinkhoff et al. 2001). I did not find information on wealthier populations affected by HIV/AIDS except for Steinberg et al. (2002) who found that a few households in South Africa paid for the services of some caregivers. Given their income, caregivers are not in the least able to cope with the financial and time demands of home-based care that I discuss later.

The data available does not provide detailed information about the socio-demographic information of caregivers, and the available information may not be representative of the caregivers of PLWHA in southern Africa. Therefore the data does not sufficiently answer the question of who the home-based caregivers are. This highlights the problem that existing data on the characteristics of caregivers are inadequate for any meaningful estimation of the cost-effectiveness of home-based care.

WHAT SERVICES DO FAMILY CAREGIVERS PROVIDE?

Caregivers help the ill carry out activities of daily living such as feeding, bathing, dressing, transferring, toileting, and ambulating. They also assist with instrumental activities of daily living such as housework, shopping, cooking, collecting water, transportation to health facilities, and making telephone calls (Blinkhoff et al. 2001; Steinitz 2003; Akintola 2006a; Thomas Nkosi, Walter Kipp, Lory Laing, and Judy Mill 2006; Orner 2006; Sheila Shaibu 2006). Caregivers also assist with the management of instrumental activities of daily living such as managing financial and legal affairs, dealing with health or other medical personnel, fetching medication, and caring for the children of the patient and the deceased (Blinkhoff et al. 2001; Steinitz 2003; Olagoke Akintola 2004b, 2006a; Homan et al. 2005a; Nkosi et al. 2006).

A key activity for caregivers is the provision of basic nursing care. Basic nursing care includes turning bedridden patients, cleaning wounds, skin care, mouth care, massages, and bed baths (UNAIDS 2000; Akintola 2004a, 2005a). Caregivers also assist in managing incontinence and monitoring the patient's diet and medication (Nnko et al. 2000; Lindsey, Hirschfeld, and Tlou 2003; Akintola 2006a).

Caregivers also provide moral and spiritual support. Caregivers pray with patients, show love by staying with them, listening, discussing, and understanding their needs, showing compassion, patience, and tolerance (Akintola 2004a; Orner 2006). Studies have shown that patients consider such moral and spiritual support essential (Blinkhoff et al. 2001; Akintola 2004b, 2005a).

When men provide care, they often perform different activities than women such as performing only instrumental activities of daily living. In many countries across southern Africa, women perform caregiving activities in addition to their traditional roles as nurturers and homemakers (Nnko et al. 2000). While some men may be willing to provide care to ill family members, they usually lack the knowledge, skills, and confidence to care (UNAIDS 2000; Akintola 2004a, 2006a). Data from Zambia, Zimbabwe, and South Africa show that some men expressed concern about the reaction of community members if they found them doing ''unmanly duties,'' a sign of weakness in some communities (Blinkhoff et al. 2001; Varaidzo Dongozi 2005; Homan et al. 2005a; Akintola 2006a).

Women tend to perform more of the activities of daily living as well as instrumental activities of daily living (Akintola 2004a; Homan et al. 2005a). Men usually avoid personal care activities such as bathing, particularly when the patient is a woman, possibly due to cultural inhibitions and what some women caregivers perceive as men's ''lack of sensitivity or compassion'' (Nnko et al. 2000; Akintola 2004b, 2005a: 9). One respondent in the study by Homan et al. indicated: ‘‘you know males they are not that sensitive’’ (Rick Homan, Catherine Searle, Eka Esu-Williams, Mark Aguirre, Sibongile Mafata, Farshid Meidany, Corrie Osthuizen, and Liz Towel 2005b: 4). Also, women caregivers in a focus group in South Africa indicated that men look for every opportunity to abdicate caregiving responsibilities and that they felt that men were less compassionate than women (Akintola 2005a: 9). On the other hand, women carry out all personal care activities including bathing even when the patient is a man (Akintola 2004b, 2005a; Homan et al. 2005a). Basic nursing involves personal care and as such is primarily the domain of women. Men are more likely to assist with instrumental activities of daily living such as lifting patients and transporting them to healthcare facilities.

Men are usually more involved in carrying out the management of instrumental activities of daily living than any other activity (Akintola 2006a). Men are traditionally the breadwinners in the homes across the southern African region (Nnko et al. 2000; Mike M. Mtika 2001; Esther Wiegers, John Curry, Alessandra Garbero, and John Hourihan 2006). Although women can be involved in cultivation and other income-earning activities, men are more likely to give attention to working and earning an income than women. This factor generally precludes men from providing support in personal care activities but allows them to assist with finances (Nnko et al. 2000; Akintola 2004a; Homan et al. 2005a).

Despite the expectation that men will provide financial support, they may be ill, absent, dead, or incapable of providing financial support due to lack of jobs. Female-headed households are common across southern Africa.[17] In such circumstances, women have to combine the role of caregiver with that of head of household and breadwinner.[18] They may have to borrow money from neighbors and friends (Nnko et al. 2000; Tlou 2000; Chimwaza and Watkins 2004; Akintola 2004b). Studies from South Africa show that men were largely absent in many HIV/AIDS-affected households leaving the responsibility for the provision of financial support entirely to women (Akintola 2004b, 2006a; Philippe Denis and Radikobo Ntsimane 2006). One South African study shows that men who did not provide physical support with caring made demands that made women’s caring work even more burdensome. In some cases men insist that women who were already burdened with caring for the ill still carry out their regular household chores such as timely preparation of food for their spouses (Orner 2006).

The impact of HIV/AIDS on some communities in southern Africa is beginning to make men more sensitive to providing care for the ill (UNAIDS 2000; Akintola 2004b). There are a number of interventions aimed at mobilizing men to care for the ill. These programs provide training for men on caregiving and have increased their participation in various activities (Dongozi 2005; Eka Esu-Williams, Katie Schenk, Scott

Geibel, Joseph Motsepe, Anderson Zulu, Petronella Bweupe, and Ellen Weiss 2006).

What is the role of volunteers?

In response to the increasing need to provide care for the ill and dying in households and communities across southern Africa, many organizations have initiated home-based care programs. These include community-based organizations, faith-based organizations, and nongovernmental organizations. Home-based care organizations typically recruit community members and provide them with training to assist HIV/AIDS-affected households. These community members are identified as ‘‘volunteer caregivers’’ (Akintola 2006a: 239). Often the distinction between family caregivers and volunteer caregivers is blurred because volunteers belong to the same communities as family caregivers and may at the same time function as primary caregivers for members of their families (Blinkhoff et al. 2001; Akintola 2004b, 2006a). Some family caregivers eventually enroll as volunteers with home-based care organizations in order to acquire formal training (UNAIDS 2000; Akintola 2005a).

Although some care organizations use a combination of unpaid volunteers and health professionals, most depend predominantly on unpaid volunteers.[19] Home-based care programs rely so heavily on volunteers that volunteers have been described as the backbone of home-based care (UNAIDS 2000; Steinitz 2003; Akintola 2004a). However, there is no accurate data on the number of care organizations in southern African countries, let alone the proportion of volunteers involved in home-based care across the countries. Again, this study draws most of its information from qualitative studies that do not provide a sense of the proportion of people who are dependent on volunteers for the provision of care (see Emmanuel Nsutebu, John Walley, Elisabeth Mataka, and Chanda Simon 2001; Blinkhoff et al. 2001; Steinitz 2003; Edoh 2004; Akintola 2005a). An exception is Steinberg et al.’s (2002) national study in South Africa that shows that about 50 percent of households used volunteer caregivers from nongovernmental home-based care organizations.

Compared with family caregivers, the socio-demographic profile of volunteers should be easier to determine since volunteers enroll with care organizations. Yet, there are fewer surveys of volunteers than of primary caregivers. Only a few qualitative studies with small sample sizes have documented their characteristics (Sarah Bowsky 2004; Gert Marincowitz, C. Jackson, and Sam Fehrsen 2004; Akintola 2005a, 2006a).

Evidence from these studies suggests that volunteers tend to have a similar profile to that of family caregivers. Volunteers are predominantly women (Steinitz 2003; Bowsky 2004; Edoh 2004; Marincowitz, Jackson, and Fehrsen 2004; Akintola 2006a; Orner 2006). A national survey of volunteers in South Africa found that 91 percent of volunteers were women (Community Agency for Social Enquiry [CASE] 2005). While family caregivers include the very young and the elderly, volunteers are people in the productive ages between 18 and 55 (Steinitz 2003; Akintola 2006a). Thus, the use of volunteers may have less of an effect on children's education and on the health of the elderly but has implications for labor force participation as will be discussed later.

The need to involve men in care has resulted in a growing interest, among non-governmental organizations as well as faith and community-based care organizations, in training young men as volunteer caregivers. These efforts have seen mixed results (AIDS Action 1995; Steinitz 2003; Esu-Williams et al. 2006). In Namibia, efforts to recruit youth as caregivers were not as successful as originally anticipated because the youth were more interested in participating in youth education and HIV prevention programs (Steinitz 2003). This probably reflects the stigma associated with caring for someone living with HIV/AIDS and the role that gender plays in caregiving. However, a recent initiative in Zambia trained youth who were originally members of anti-AIDS clubs to carry out caregiving as part of their activities (Esu-Williams et al. 2006).

Most volunteers have levels of education similar to those of family caregivers (Blinkhoff et al. 2001; Steinitz 2003; Akintola 2004a, 2005a). Some volunteers have attained higher levels of education, and many are retired nurses and teachers while a few are unemployed university graduates (UNAIDS 2000; Bowsky 2004; CASE 2005; Akintola 2006a).

Many volunteers are themselves affected with HIV/AIDS or are related to a PLWHA (Steinitz 2003; Olagoke Akintola 2004a, 2005b; HelpAge International 2004). An official of a home-care organization in South Africa estimated that 95 percent of volunteers in their program were either infected or affected by HIV/AIDS (Akintola 2004a). Similar assertions have been made in studies on Namibia, South Africa, and Zambia, though only a few of these studies could confirm these claims (UNAIDS 2000; Blinkhoff et al. 2001; Steinitz 2003). Pathfinder International's (2006) study on Tanzania also found that some HIV-positive persons received training and served as volunteers.

Volunteer caregivers often act as secondary caregivers to patients. They train family members to provide care, and they provide supervision and a range of support services to these families. Volunteers link patients and their families with sources of spiritual support such as churches or mosques. They provide counseling, bereavement counseling, and health education and assist with transporting patients to health facilities (Akintola 2004a; Bowsky 2004). Most home-based care programs use volunteers as adherence monitors for tuberculosis treatment, and a few use them to monitor adherence to antiretroviral treatment (UNAIDS 2000; Yvonne Mulenga and David Lungowe 2005; Shaibu 2006). Volunteers in Botswana and South Africa assist with applications for social grants (Lindsey, Hirschfeld, and Tlou 2003; Olagoke Akintola 2006b; Shaibu 2006).

In households where ill people live alone or with children too young to provide care, volunteers will often become the primary caregivers. In a study of South Africa, Steinberg et al. (2002) found that 8 percent of HIV/AIDS-affected households had no one to provide care for the PLWHA.

WHAT MOTIVATES PEOPLE TO BECOME HOME-BASED CAREGIVERS?

Family caregivers provide care for a range of reasons: among these are love for the ill person, a need to see improvement in the life of the ill, and the need to conform to social norms that prescribe that women be the nurturers and therefore the care providers. The benefits of providing unpaid care could be emotional, spiritual, or economic. In general, there is no expectation of immediate pecuniary reward, although, as feminist economists have noted, caregiving could represent a form of saving (Ertuk and Catagay [1995] cited in Irene van Staveren [2005]) or investment (van Staveren 2005). The family caregiver may save some amount of money by providing care to the relative at home instead of paying a nurse or institution. In countries that charge user fees for healthcare, caregivers may save on costs that would otherwise have been spent on hospital care. With few exceptions, family and volunteer caregivers receive training free of charge (Akintola 2006b).[20] Hence, caregiving could be a form of human capital investment that has potential for short or long-term returns.[21]

What motivates non-family members to provide care without receiving remuneration? Daniel Batson, Nadia Ahmed, and Jo-Ann Tsang (2002) differentiate four types of motivation for community involvement: altruism, to increase the welfare of individual(s); collectivism, to increase the welfare of a group; egoism, to increase one's own welfare; and principalism, to uphold moral principles.

Altruism is a central motive reported in the few studies that survey motivation. (Akintola 2004b, 2005a; Edoh 2004). Individuals who have cared for their own family members find it easy to empathize with family caregivers and want to give a helping hand. Many volunteers have been recruited through churches and work for faith-based organizations and are motivated to care for religious reasons. Also important is collectivism. Some volunteers are motivated by a desire to assist in stemming the impact of the disease that is ravaging their communities (UNAIDS 2000; Akintola 2004b).

In addition, volunteer caregivers may be motivated by egoism. Some may volunteer to seek knowledge and skills on HIV/AIDS prevention and care. Others hope someone else will reciprocate their gesture if they fall ill and find themselves in need of care and support. They may hope that volunteering will give them improved access to antiretroviral treatment and recognition in the community (UNAIDS 2000; Blinkhoff et al. 2001; Olagoke Akintola 2004b, 2005a, 2005b). Qualitative studies on South Africa show that some people volunteer in order to keep themselves busy. A participant in a focus group in South Africa said he did not want to stay home doing nothing because the ‘‘devil finds work for idle hands to do’’ (Akintola 2005a: 16). Individuals enroll in the volunteer program while waiting to get employed elsewhere (UNAIDS 2000; Akintola 2005a). Some people are motivated by the hope that volunteering will help them find a job in healthcare. In South Africa, for instance, some volunteers believe that home-based care organizations or the state will eventually employ them as community health workers, and that they will ‘‘someday receive payment for their labour’’ (Akintola 2004b: 148). Indeed, some volunteers have been able to secure employment with home-based care organizations or the state as a consequence of the skills and hands-on experience acquired through care work (UNAIDS 2000; Akintola 2004b, 2006b). Yet others volunteer based on the principle that it is morally wrong to sit by and watch people die without providing care and support for them. They believe that everyone deserves to be treated with dignity (UNAIDS 2000; Akintola 2005a). Ultimately, these different motivations are not mutually exclusive but interact in complex ways to influence the decision to volunteer.

WHAT ARE THE IMPLICATIONS OF HOME-BASED CARE FOR CAREGIVERS?

The costs of home-based care for HIV/AIDS-affected households and unpaid caregivers fall into three broad categories: financial costs, opportunity costs, and physical and emotional costs. The financial costs are the direct dollar outlays associated with home-based care compared to what would have been incurred had the patient been in institutional care. The opportunity costs associated with caregiving refer to the cost of time that caregivers cannot spend on other activities (Folbre and Nelson 2000; Debbie Budlender 2005). They also include the value of opportunities that caregivers relinquish to provide home-based care. The physical and emotional costs include the mental and practical difficulties that caregivers experience in carrying out their tasks, sometimes defined as the burden of care. The literature suggests that home-based care is associated with an increase in physical, emotional, social, and economic costs both for caregivers and other family and community members (Nnko et al. 2000; Nkosi et al. 2006; Orner 2006).

Financial costs

The financial impact of HIV/AIDS on households in southern Africa is well documented, though little is known about the incremental costs incurred as a consequence of home-based care (see Gabriel Rugalema 1998, 2000; John Stover and Lori Bollinger 1999; Booysen 2002; Jeff Gow and Chris Desmond 2002; Akintola 2004a). It is therefore critical to distinguish between the financial costs that families incur as a result of HIV/AIDS and those costs they incur as a result of home-based care.

Families spend substantial amounts of money on healthcare and purchasing specially recommended food for the ill (Steinberg et al. 2002; Akintola 2004a; Chimwaza and Watkins 2004). Steinberg et al. (2002) found that affected households spent a third of their income on medical related expenses. A HelpAge International study (2004) of older caregivers in Tanzania shows that the cost of caring for HIV/AIDS patients was more than five times the amount that an older person could earn in a day through petty trading, brewing and selling alcohol, harvesting and selling forest products such as firewood, wild fruits, and vegetables, occasional transactional sex, and selling family property.

Home-based care also increases the need for water, disinfectants, and soaps (Hansen et al. 1998; Nnko et al. 2000; Lindsey, Hirschfeld, and Tlou 2003; Akintola 2004b; Bowsky 2004; Chimwaza and Watkins 2004). In certain communities like Tanga, Tanzania, caregivers spend a substantial portion of their income on purchasing water for washing and dressing wounds (HelpAge International 2004). Given that most HIV/AIDS-affected households are poor and lack access to infrastructure, the cost of water may be considerable. For example, Laila Azari, Dianna Braunner, Luyi Chen, Karen Crow, Julie Evans, Graziano Graziussi, Fernando Gubbins, Kata Kiss, Laura Pitarys, Dana Puia, Karen Tarrant, Alper Tunca, Chimi Wangchunk, and Charis Varnum (2004) estimate that care for an HIV/AIDS patient often requires twenty-four buckets of clean water a day.

It is not clear what proportion of these costs the caregivers would still incur if the patients were in institutional care. At least some proportion of the costs of medicine, medical supplies, food, and water would have been incurred even if the patients were in institutional care. However, there may be important differences. For example, the amount of water required to provide home-based care for an HIV/AIDS patient may not have been necessary if the patient were in institutional care. The cost of drugs, bandages, diapers, and other medical supplies incurred by the family should be distinguished from those provided by hospitals. However, few studies distinguish between these costs. (See Hansen et al. 1998; Gillian Moalosi, Katherine Floyd, Jabulani Phatshwane, Themba Moeti, Nancy Binkin, and Thomas Kenyon 2003).

In the case of volunteer caregivers, the financial cost of home-based care is, in principle, easier to determine since they would have no expenditures for care were they not volunteers, yet I could not find any study that attempted to quantify the direct outlays of volunteers. Home-based care imposes financial burdens for the volunteers, who sometimes spend their own personal money to buy food or medication for their patients when it is not available from the government or care organizations (Blinkhoff et al. 2001; Akintola 2004b, 2005a; Bowsky 2004; Edoh 2004). In Lesotho, volunteer caregivers reported having to give food from their own gardens or other material items such as blankets and soap to their patients (Bowksy 2004). Similar findings have been reported in Zambia, South Africa, Tanzania, and Botswana where volunteers spent their money to buy food, medication, and other items for their patients (Blinkhoff et al. 2001; Lindsey, Hirschfeld, and Tlou 2003; Homan et al. 2005b). In a South African study, volunteer caregivers had to borrow money to take care of the financial needs of their patients (Akintola 2004a). These expenditures are all directly attributable to home-based care for persons affected with HIV/AIDS.

Opportunity costs of care

Following the work of Carolyn Zhu, Michael Moore, and Elizabeth Clipp (2003) on informal care for people with dementia, opportunity costs incurred by caregivers can be defined as the incremental cost of time spent in providing home-based care, that is, the difference between the cost of the amount of time that caregivers spend in home-based care versus the amount of time that caregivers would have had to spend caring had the patient been in institutional care.

Although there are a few surveys that document how much time it takes to care for HIV/AIDS patients (Hansen et al. 1998; Bachmann and Booysen 2003), none of the available studies account for the incremental amount of time care providers spend as a consequence of home-based care. Furthermore, I found no systematic documentation of how much time each caregiver spends in providing each form of care. Time-use surveys, which should ideally provide comprehensive information about individual caregivers' time use, usually ask questions about unpaid care work in general but not specifically about HIV/AIDS-related care work. There is therefore no disaggregated data accounting for unpaid HIV/AIDS care. Hence, one cannot carry out comprehensive estimates of opportunity costs of care for individual members of households who provide care or conduct a meaningful comparison of alternative uses of time for men and women.

Available estimates of the hours required per day vary widely. A Zimbabwean study on the costs of home-based care estimates that, in late 1994 and early 1995, caregivers spent on average 2.5–3.5 hours per day in providing care and it estimated an opportunity cost of US$22 per month using the minimum wage at the time of the survey (Hansen et al. 1998). However, the study does not provide information on the kinds of employment that caregivers had or specific activities that they gave up in order to perform care. Bachmann and Booysen's (2003) study on South Africa estimates that it took on average 5 hours per day for caregivers to provide care, but it does not provide information on how much time it took an individual to perform specific tasks. Qualitative studies indicate that caregivers spend between 3–12 hours per day caring for bedridden patients (Nnko et al. 2000; Lindsey, Hirschfeld, and Tlou 2003; Chimwaza and Watkins 2004) while those caring for incontinent patients or patients suffering from diarrhea usually need to be on standby 24 hours a day to change nappies and soiled clothes (Nnko et al. 2000; HelpAge International 2004; Akintola 2006a; Orner 2005).

Caregivers in the productive age group lose opportunities to provide income when they provide care (Steinberg et al. 2002; Akintola 2004b). Some who are in formal employment may lose their jobs or have to reduce the time that they spend working, resulting in reduced income (Carolyn Baylies 2002; Akintola 2004a). Those who are self-employed in informal jobs such as hairdressing and petty trading also report missed opportunities to earn income while they provide care (Akintola 2004b). In a South African survey, 40 percent of primary caregivers reported taking time off from formal or informal employment or schooling to take care of the ill person. In 12 percent of cases, time was taken from formal employment while in 10 percent of cases time was taken from other income generating activities (Steinberg et al. 2002). In Tanzania, Malawi, Swaziland, and Zambia, where subsistence-farming activities constitute a major source of livelihood and food security, caregiving severely disrupts farming activities and undermines household food security (Baylies 2002; HelpAge International 2005; Pathfinder International 2006; Wiegers et al. 2006).

Opportunity costs will depend on labor-market opportunities available to the caregiver prior to assuming caregiving duties. Because most studies show that HIV/AIDS usually affects poor households in which the primary caregivers are usually not in formal or informal employment, the value of time forgone for care is usually invisible. In other words, caregivers who are unemployed and not involved in subsistence agriculture/subsistence production and who have low-paid labor-market opportunities do not necessarily forego time from productive activities (market or subsistence production). Instead, they lose time spent in ''leisure'' or other social activities. Unemployed caregivers will incur some opportunity cost in terms of the cost of the amount of time that they give up from other household work or the care of other household members (who are healthy or have other illnesses) to care for PLWHA.[22] However, unemployed caregivers may also improve their labor-market opportunities through investments in human capital. Both family and volunteer caregivers may benefit from the skills acquired from home-based care training and hands-on experience as a caregiver. They could use these skills to not only provide care to their family members (Nnko et al. 2000; UNAIDS 2000; Akintola 2005a) but also to community members, in which case the skills acquired could be thought of as what Paula England and Nancy Folbre have referred to as ''public goods'' for which they would expect no financial reward (1999: 45).[23] If the caregiver had few skills, was unemployed, and had low labor-market opportunities, the investment in human capital may well compensate for the value of foregone time.[24] In households where children serve as primary caregivers, some have to be withdrawn from school. Children who serve as secondary caregivers may not be withdrawn from school but may, as a result of their caregiving duties, absent themselves from school occasionally and have little time to carry out school assignments or study at home. Anecdotal and qualitative data support the assertion that children drop out of school to provide care (Tlou 2000; Baylies 2002; Lindsey, Hirschfeld, and Tlou 2003; Akintola 2004b). Again, there is little information on the prevalence of this phenomenon. Most quantitative studies do not identify the reasons for withdrawal of children from schools (Samson 2002; Steinberg et al. 2002; Paul Bennell 2005). One exception is a study by Steinberg et al. (2002), which found that one-fifth of the study population provided care for HIV/AIDS patients during time normally spent attending school. Still, this study and others do not provide information on how many children were withdrawn from schools to provide care because they aggregate information on children who drop out of school as a result of poverty and other difficulties with those withdrawn specifically to provide care (Steinberg et al. 2002; Bennell 2005).

Physical and emotional costs

Caregiving is demanding and imposes physical strain on the caregiver. Caregivers often have to walk long distances, sometimes on hilly and difficult terrains, to fetch water to patients' homes (HelpAge International 2004; Catherine Campbell, Yugi Nair, Sibongile Maimane, and Zweni Sibiya 2005). They sometimes carry ill people on their back to toilets or in wheelbarrows or bicycles to health facilities. Caregivers report headaches, body aches, and loss of libido (Akintola 2006a; Orner 2006). The physical toll of caring on older caregivers or on caregivers who themselves are affected with HIV/AIDS can be great. They often neglect their own deteriorating health and lack anyone to provide care for them (Lindsey, Hirschfeld, and Tlou 2003; Akintola 2006a). Caregivers may also face risk of infection with tuberculosis or HIV (Lindsey, Hirschfeld, and Tlou 2003; HelpAge International 2004; Akintola 2006a).

There is also an emotional burden for caregivers who have to watch their patients deteriorate in health and die. Volunteer caregivers often develop close bonds with their patients during the period of caring and this makes it emotionally devastating when they lose their patients (Akintola 2006a; Shaibu 2006). In addition, caregivers incur social costs as a result of the disease's stigma. Caregivers usually do not disclose the status of their patients to neighbors or community members and may have to provide care alone, leading to social isolation (Akintola 2005a; Orner 2006). There may also be discrimination against the caregivers if community members find out that the patient is suffering from HIV/AIDS. (Nnko et al. 2000; Blinkhoff et al. 2001; Lindsey, Hirschfeld, and Tlou 2003; Akintola 2006a).

CONCLUSION

This review provides insight into caregiving for PLWHA in southern Africa with a specific focus on identifying issues needed to provide comprehensive estimates of the costs borne by caregivers. The study shows that the available information on caregiving in the region is grossly inadequate for carrying out proper estimation of costs. I found few cost studies, and none of the studies provide information on all the critical components of costs to caregivers and their families. The current literature particularly neglects the hidden costs, such as children who drop out of school or miss study time to provide care, and it also ignores the effect of providing care on market and home-production activities. There is need for comprehensive cost studies that compare the costs to each stakeholder under various models of home-based care compared with hospital care.[25]

Clearly, attempts to calculate more comprehensive costs of home-based care require more qualitative and quantitative research that acknowledges all stakeholders in home-based care and that documents the costs, benefits, and utility derived by each of the stakeholders. Moving closer to the true cost of home-based care will require the collection of qualitative and quantitative data on a variety of themes.

- There is a need for studies that use representative samples. Most of the available evidence on home-based care is based on small nonrandom samples, sometimes drawn with the help of home-based care programs. Thus, little is known about the households that do not access these services because they are not located in an area served by a home-based care organization. In order to carry out a full accounting of costs, national household surveys should include questions on how care is provided for chronically ill people with HIV/AIDS and the time each household member devotes to care. This will enable the estimation of time use by primary caregivers as well as secondary caregivers who have been relatively neglected in the literature.

- There are no quantitative studies of volunteer caregivers. Such studies should explore the cost of time spent by volunteers, both those associated with home-based care programs and those working independently. The financial outlays of volunteers should also be documented.
- Given that many of the affected households are poor and dependent on subsistence agriculture or home production, there is a need for studies that look at the impact of home-based care on the agricultural sector and on home production.
- Surveys of school dropouts should track the reasons for dropping out, distinguishing among those who drop out because of lack of money, because they are required to perform care, or for other reasons.

As Susan Himmelweit has noted (2007), one of the distinguishing characteristics of caregiving is that it involves the production of an output that is not separable from the person delivering it. Even if hospital-based care requires less financial outlay, family caregivers may prefer to care for their relatives because of the utility derived from caring, and PLWHA may derive greater emotional or spiritual support from a family caregiver or a community volunteer than from a healthcare worker in institutional care. Like other health programs that require community participation, home-based care produces elements of social capital such as trust, honesty, and reciprocity. Additional qualitative and quantitative studies on the motivations for caregiving among family members and volunteer caregivers and the implications for social capital formation as well as the costing of care are needed.[26]

In addition, there is a need to compare the impact on the health of both the patient and the caregiver under different care regimes. Quality of life surveys are needed to assess the qualitative differences between home-based and hospital-care for both patients and caregivers. Otherwise, it will be possible for cost studies to find that home-based care is cheaper than institutional care while ignoring the fact that the quality of care may be lower than that of hospital care, or that a cost burden is imposed on caregivers. Assessments with this perspective could support advocacy to prevent governments from transferring the entire burden of care to caregivers and their families.

To conclude, one must be careful not to think of home-based care as cheaper than institutional care since there is no evidence to support this assertion. Home-based care may well be more expensive than institutional care if both forms of care provide similar quality of care for patients, and all other costs are estimated. In the absence of comprehensive assessments of costs of home-based care compared with the cost of institutional care, the wisdom of enacting home-based care policies remains questionable.

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NOTES

[1] Cost studies estimate the cost-effectiveness of home-based care compared with institutional care.

[2] I adopt a broad definition of people living with HIV/AIDS to include all people infected with HIV/AIDS notwithstanding the stage of the disease.

[3] According to the World Health Organization (2002) home-based care refers to the provision of health services by formal and informal caregivers in the home to restore and maintain a person's maximum level of comfort, function, and health including care toward dignified death.

[4] Although different countries in the region have drawn up separate policies, they are very similar and aim to achieve the same purpose: the reduction of patients' length of stay in hospital.

[5] Studies show that PLWHA make up a substantial proportion of public health facility users across sub-Saharan Africa.

[6] Susan Fox, Cally Fawcett, Kevin Kelly, and Pumla Ntlabati 2002; Kristian Hansen, Godfrey Woelk, Helen Jackson, Russell Kerkhoven, Norah Manjonjori, Patricia Maramba, Jane Mutambirwa, Ellen Ndimande, and E. Vera 1998; Gillian Moalosi, Katherine Floyd, Jabulani Phatshwane, Themba Moeti, Nancy Binkin, and Thomas Kenyon 2003. Moalosi et al. (2003) study the cost-effectiveness of home-based versus hospital care for chronically ill tuberculosis patients, focusing on only some components of care associated with HIV/AIDS.

[7] Southern African Development Community is the umbrella association for countries in southern Africa and has fourteen member countries.

[8] In order to retrieve published articles for the review, I conducted a keyword search on the Internet using various search engines, including Medline, Aidsearch, Academic Search Premier, Ebscohost, and Google Scholar. To search for unpublished articles, reports of organizations and other policy documents, I used Google and Yahoo search engines. Both searches used different combinations of the following Keywords: home-based care, home-care, AIDS care, unpaid care, community-based care, informal AIDS care, social, economic, impact, households and family. In addition, I solicited unpublished materials from organizations and colleagues working on

home-based care. Given the paucity of data on home-based care, I left the criteria for inclusion of studies very flexible.

[9] Two of the studies reviewed sampled caregivers for people with HIV/AIDS as well as for patients with other chronic illnesses. (R. Ndaba-Mbata and Esther Salang Selioilwe 2000; Elizabeth Lindsey, Miriam Hirschfeld, and Sheila Tlou 2003: 493).

[10] Given that antiretroviral therapy is not yet available to most PLWHA in southern Africa, PLWHA may require care at different times during the illness trajectory; hence the use of the term patients.

[11] A South African study found that 82 percent of primary caregivers were immediate family members (Rick Holman, Catherine Searle, Eka Esu-Williams, Mark Aguirre, Sibongile Mafata, Farshid Meidany, Corrie Osthuizen, and Liz Towel 2005a).

[12] Home-based care organization is a broad term that includes faith-based organizations, community-based organizations, and non-governmental organizations providing home-based care services.

[13] I elaborate on this point in the section on costs of unpaid care.

[14] The government of South Africa provides various grants for different vulnerable groups: old age grants for the elderly; childcare grants for children who have poor parents, foster care grants for foster children, and disability grants for disabled people.

[15] Godfrey Woelk, Helen Jackson, Russell Kerkhoven, Kristian Hansen, (Norah) Manjonjori, Patricia Maramba, Jane Mutambirwa, Ellen Ndimande, and E. Vera 1995; Steinberg et al. 2002; Lindsey, Hirschfeld, and Tlou 2003; Sarah Bowsky 2004; Chimwaza and Watkins 2004; HelpAge International 2005.

[16] I am not suggesting that private paid care is an organized or widespread practice in these countries. Indeed, little is to be found on the use of paid care for persons living with HIV/AIDS in southern Africa. However, a few studies, mainly on South Africa, document that some affected households employ the services of home-based caregivers in return for financial remuneration (see Steinberg et al. 2002; Community Agency for Social Enquiry [CASE] 2005).

[17] The reasons for the high prevalence of female-headed households include non-marriage, high death rates as a result of AIDS, and high divorce rates (Eleanor Preston-Whyte 1978; Steinberg et al. 2002; Lindsey, Hirschfeld, and Tlou 2003; Chimwaza and Watkins 2004; Homan et al. 2005a; Akintola 2006a; Philippe Denis and Radikobo Ntsimane 2006).

[18] Robson 2000; Jeff Gow and Chris Desmond 2002; Lindsey, Hirschfeld, and Tlou 2003; Chimwaza and Watkins 2004; Akintola 2006a; Wiegers, Curry, Garbero, and Hourihan 2006.

[19] The different models of home-based care make use of volunteers to varying degrees and provide different levels of services and resources to their patients. For a fuller discussion of these different models, see Russel and Schneider 2000; Akintola 2004a; Homan et al. 2005; Naidu 2005; and Busisiwe P. Ncama 2005.

[20] There is anecdotal evidence in South Africa to suggest that some volunteers pay for their own training in order to qualify for government positions (Akintola 2006b).

[21] Given the prevalence of HIV/AIDS and the need for care, acquisition of skills is potentially remunerative for the short and long term.

[22] Caregivers who are employed or involved in subsistence production will, in addition to loss of time from employment or subsistence production, still lose time for ‘leisure’ and home production.

[23] Although volunteers may not enjoy direct financial rewards for providing care, the society is able to enjoy some savings in the cost of care. The training provided could therefore be thought of as an investment for the public good.

[24] The converse could also be the case. Caregivers who are unemployed could miss potential opportunities for human capital investments (for example, other education

and training opportunities) while providing care, in which case the caring skills acquired may not compensate for the cost of time lost in caregiving.

[25] Note that the cost of care varies with the severity and duration of illness, size of affected family, and quality of care provided.

[26] Social capital refers to the norms and networks that enable collective action. It encompasses institutions, relationships, and customs that shape the quality and quantity of a society's social interactions. It has five key dimensions: groups and networks, trust and solidarity, collective action and cooperation, social cohesion and inclusion, and information and communication (World Bank 2000).

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APPENDIX

Table 1 A list of the documents reviewed for the study

Sponsoring organization/ author, year	Country	Study setting	Methods/design	Study population and sample size	Sampling technique	Instrument and data collection procedure
Akintola (2004a)	South Africa	2 peri-urban sites (townships)	Qualitative study using ethnographic methods	21 primary & 20 volunteer caregivers of PLWHA & home-based care coordinators	Purposive snowball sampling	In-depth interviews; participant observations; focus groups and workshops
Akintola (2004b)	South Africa & Uganda	Several settings including peri-urban and urban areas	Rapid qualitative appraisal	Key informants, home care managers, counselors, nurses, volunteers, & PLWHA	Purposive sampling of care organizations	Face-to-face and telephone interviews, focus groups, and review of unpublished documents
Akintola (2005a)	South Africa	1 urban site, 2 peri-urban sites, and 1 informal settlement	Qualitative study	37 volunteer caregivers of PLWHA	Volunteer purposive sampling	In-depth interviews and focus groups sessions
Akintola (2006a)	South Africa	2 peri-urban sites (townships)	Qualitative study using ethnographic methods	21 primary & 20 volunteer caregivers of PLWHA & home-based care coordinators	Purposive snowball sampling	In-depth interviews; participant observations; focus groups and workshops
Bachmann and Booysen (2003)	South Africa	Rural and urban sites	Quantitative cohort study	202 AIDS-affected and 202 unaffected households	Purposive sampling	Survey using structured questionnaires
Blinkhoff et al. (2001)	Zambia	Semi-rural townships	Qualitative case study	Volunteer caregivers, PLWHA, family caregivers and other stakeholders in the home-care program of the Ndola Catholic Dioscese	Purposive sampling	Interviews with volunteers and stakeholders
Bowsky (2004)	Lesotho	Rural & urban sites	Rapid qualitative appraisal	Care organization staff, volunteer caregivers, PLWHA and the Lesotho Senate AIDS committee	Purposive sample	Review of documents, focus group sessions, observations, interviews

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Table 1 (*Continued*)

Sponsoring organization/ author, year	Country	Study setting	Methods/design	Study population and sample size	Sampling technique	Instrument and data collection procedure
Campbell, Nair, Maimane, and Sibiya (2005)	South Africa	Rural site	Qualitative case study	Volunteer caregivers, PLWHA, and other stakeholders in community care from public and private sectors	Participatory research with all stakeholders	In-depth interviews, focus group sessions
Chimwaza and Watkins (2004)	Malawi	Rural site	Qualitative study of primary caregivers	15 primary caregivers of PLWHA	Purposive sample recruited with assistance from community headman and other informants	Interviews
CASE (2005)	South Africa	Rural and urban sites	Qualitative and quantitative study	Care organizations volunteer and caregivers	Purposive sampling of care organizations and caregivers	Questionnaire, interviews
Edoh (2004)	Zambia	Peri-urban slums	Qualitative study	15 volunteer caregivers	Purposive sampling from 4 care organizations	Interviews, focus group reflection sessions
Esu-Williams et al. (2006)	Zambia	Assessment of an intervention to build young people's capacity to provide home-based care	Quantitative and qualitative evaluation study	Youths who had previously received training as caregivers as part of an intervention	Purposive sampling	Interviews and questionnaires
Gow and Desmond (2002)	South Africa	Rural site	Quantitative study	178 households belonging to 3 categories: (1) contained orphans, (2) people suspected to have HIV/AIDS and (3) control containing neither of 1 or 2	Purposive sampling	Household survey using structured questionnaire
Hansen et al. (1998)	Zimbabwe	Urban and rural sites	Quantitative cost study	60 patients and caregivers receiving care from a variety of care	Purposive sampling	Questionnaire and review of records

(*continued*)

Table 1 (*Continued*)

Sponsoring organization/ author, year	Country	Study setting	Methods/design	Study population and sample size	Sampling technique	Instrument and data collection procedure
				organizations		
HelpAge International (2004)	Tanzania	Rural and semi-rural sites	Qualitative study	1,983 participants: elderly caregivers of PLWHA and AIDS orphans and a variety of stakeholders from the health sector and civil society	Purposive sampling	Interviews, seasonal calendars, institutional mapping, focus group sessions, observations, workshops and desk review
HelpAge International (2005)	Mozambique, South Africa and Sudan	Rural and semi-rural sites	Qualitative study	Elderly caregivers of PLWHA and AIDS orphans	Purposive sampling	Interviews
Homan et al. (2005a)	South Africa	Rural and semi-rural sites	Qualitative and quantitative study	Care organizations providing varying degrees of support to PLWHA	Purposive sampling of care organizations	Household survey; focus groups and interviews
Homan et al. (2005b)	South Africa	Rural, semi-rural, and urban sites	Costing study employing qualitative and quantitative methods	Patients, formal caregivers	Purposive sampling of care organizations and households	Household survey; focus group sessions, interviews, review of financial records and statistics
Kipp et al (2006)	Democratic Republic of Congo	Urban site	Quantitative study	80 family caregivers	Random sampling from list of home care clients	Survey using semi-structured questionnaire
Lindsey, Hirschfeld, & Tlou (2003)	Botswana	2 rural sites and 1 urban site	Qualitative study	15 primary caregivers of PLWHA; 20 primary caregivers of people with other chronic illnesses; 35 key informants: volunteers, nurses, social workers, home-care organizations, government health officials	Convenience sampling	Interviews
Marincowitz, Jackson, & Fehrsen (2004)	South Africa	Municipal containing mostly rural villages	Qualitative study	14 volunteer caregivers of PLWHA	Purposive sampling	1 focus group session
Moalosi et al. (2003)	Botswana	Urban site	Quantitative study	50 family caregivers of TB patients	Purposive sampling	Questionnaires, review of records, interviews with

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Table 1 (*Continued*)

Sponsoring organization/ author, year	Country	Study setting	Methods/design	Study population and sample size	Sampling technique	Instrument and data collection procedure
						stakeholders
Mulenga & Lungowe (2005)	Zambia	Urban site	Qualitative study	Volunteer caregivers serving as antiretroviral adherence monitors	Purposive sampling	Interviews, reviews of records, stakeholder interviews/ feedback
Ndaba-Mbata and Seloilwe (2000)	Botswana	Rural site	Qualitative study	15 family caregivers of chronically ill patients	Purposive sampling	Interviews
Nkosi et al. (2006)	Democratic Republic of Congo	Urban site	Qualitative study	12 primary caregivers; 6 home-based care workers & 5 key informants	Volunteer purposive sampling with assistance of home care organizations	Focus group sessions
Nnko et al. (2000)	Tanzania	Rural site	A qualitative study of family caregivers of PLWHAs	21 primary caregivers who have provided care for at least more than one PLWHA in the terminal stage of illness	Purposive sampling with assistance of home-care volunteer	Interviews
Nsutebu et al. (2001)	Zambia	Urban, peri-urban site	Quantitative and qualitative case study	2 home-based care organizations: program managers, administrative staff, community nurses, community volunteers, family members, and PLWHA	Purposive selection of care organizations	Review of program reports; in-depth interviews and observation of program activities
Orner (2005; 2006)	South Africa	1 informal settlement; 2 peri-urban sites (townships)	A qualitative study	45 primary caregivers of PLWHA	Purposive sampling	In-depth interviews
Pathfinder International (2006)	Tanzania	Several urban, peri-urban, rural sites	Qualitative study	Primary caregivers, PLWHA, community health workers, health & officials	Purposive sampling	Interviews, focus group sessions key informant interviews, literature review
Robson (2000, 2004)	Zimbabwe	Urban sites	Qualitative studies of child caregivers	Child caregivers	Purposive sampling	Interviews
Russel and Schneider (2000)	South Africa	Several urban, peri-urban and rural settings	Rapid qualitative appraisal	Several care organizations	Purposive sampling	Interviews and observation
Samson (2002)	South Africa	AIDS-affected community in a	Quantitative and qualitative study	30 households containing children suffering from	Purposive sampling	Survey using structured questionnaire and

(*continued*)

Table 1 (*Continued*)

Sponsoring organization/ author, year	Country	Study setting	Methods/design	Study population and sample size	Sampling technique	Instrument and data collection procedure
		rural setting		malnutrition		qualitative interviews
Shaibu (2006)	Botswana	Rural setting	A qualitative case study on the establishment of a home-based care outreach program	A selected home-based care organization as case study	Purposive sampling	Interviews
Steinberg et al. (2002)	South Africa	Urban and rural sites	A national survey of the impact of HIV/AIDS on affected households	771 AIDS affected households	Purposive sampling	Survey: structured questionnaire
Steinitz (2003)	Namibia	Not specified	A case study of the role of volunteer caregiver in a faith-based care program	A faith-based AIDS care and support organization: Catholic AIDS Action	Documentation of the experiences of a wide range of stakeholders in home-based care	Review of experiences and review of literature
Tarimo (2004)	Tanzania	Urban setting	Qualitative case study of 1 home-care organization	20 family caregivers; 6 PLWHA; 8 volunteer caregivers; 6 home-care nurses	Purposive sampling with assistance of home-care nurse	In-depth interviews; focus group discussions; observations
Tlou (2000)	Botswana	Rural and urban sites	A qualitative study of impact of caregiving on girls	Family caregivers of PLWHA	Purposive sampling	Interviews
UNAIDS (2000)	South Africa and Uganda	Several urban, peri-urban, and rural settings	Qualitative study; rapid assessment	Several care organizations	Purposive sampling	In-depth interviews
Zimba and Mclnerney (2001)	Malawi	Urban	Quantitative study	36 primary caregivers of children aged 0–12 months	Random sampling of primary caregivers registered with home-care organizations	Structured questionnaire