

United Nations
Division for the Advancement of Women
Expert Group Meeting on “Equal sharing of
responsibilities between men and women, including
care-giving in the context of HIV/AIDS”
United Nations Office at Geneva
6-9 October, 2008

Towards equal sharing of AIDS caring responsibilities: Learning from Africa

Olagoke Akintola*

Division for the Advancement of Women
Department of Economic and Social Affairs
United Nations, New York
Fax: (212) 963-3463
daw@un.org
<http://www.un.org/womenwatch/daw>

* *The views expressed in this paper are those of the author and do not necessarily represent those of the United Nations.*

TOWARDS EQUAL SHARING OF AIDS CARING
RESPONSIBILITIES: LEARNING FROM AFRICA

PREPARED FOR THE UNITED NATIONS DIVISION FOR THE
ADVANCEMENT OF WOMEN “EXPERT MEETING”

Geneva, Switzerland
October, 2008

Olagoke Akintola
School of Psychology
University of KwaZuluNatal
Durban, South Africa

1. Introduction

Sub-Saharan Africa accounts for a disproportionate (67%) burden of HIV/AIDS. (UNAIDS, 2008). The impact of HIV/AIDS is more severe at the individual/family and community levels where caregiving for people living with HIV/AIDS (PLWHA) represents one of the greatest burdens on families¹. Families are unable to cope with the provision of care for the ill for a number of reasons. The long drawn out nature of the disease requires that individuals allocate substantial amount of time as well as financial and material resources well beyond that required for normal day to day reproductive activities. Second, families often do not have the necessary skills for providing adequate care and support for the ill (Akintola, 2008a). Given that the impact of HIV/AIDS is more severe among poor rural households² and communities (UNAIDS, 2008), the burden of caring is inevitably borne by the poor. At the same time, patients with AIDS represent between 45-70 per cent of public health facility users in the most affected countries across Africa (Shisana et al 2002; Shaibu 2006)³. This has exposed the lack of capacity in the public health systems even worsening its capacity to cope. In response countries with high prevalence of HIV/AIDS are making home-based care (HBC) central to their public health and AIDS policies. Home-based care⁴ reduces contact between the ill and public health institutions thereby causing a major shift in the primary place of care for PLWHA from public institutions to the very poor families who make use of public health facilities and from public health workers to the very poor women who previously carried a disproportionate burden of reproductive work. Within households and communities women experience a disproportionate share of the burden of caring for the ill (UNAIDS, 2008). This is a point that I shall return to in a subsequent section.

In this paper I outline the additional responsibilities created by the HIV/AIDS pandemic, discuss the role of home-based care in mitigating and exacerbating the unequal sharing of these responsibilities among men and women. I then discuss the role of support in mitigating the burden of care and explore possible ways of ensuring a more equitable sharing of caring responsibilities in the AIDS context.

2. Responsibilities peculiar to the HIV/AIDS context

A legitimate question that one may ask is why is caregiving responsibilities different in the context of AIDS? The presence of a person(s) with HIV/AIDS in a family necessitates the performance of a range of caring⁵ responsibilities over and above normal domestic and care work. These activities could be classified into two broad categories: 1) care of family members including orphans, assistance with activities that patients are unable to do because of their incapacity: depending on their stage of illness they may need to be assisted in carrying out activities of daily living, instrumental activities of daily living, household chores such as cooking, which are bound to increase because of the needs of the patients (Akintola, 2005a), managing patients' other legal or business/financial affairs, assistance with securing documentation necessary to access state grants. Water is a key element in the care of patients and incontinent patients require more water than usual (Ngwenya and Kgathi 2006; Akintola, 2008a) However, water is not readily accessible in many rural communities in Africa which means that people may have to fetch water from rivers, wells, boreholes or public standpipes which may be long distances away from home. 2) Basic nursing and other forms of support: turning patients, cleaning wounds, skin care, mouth care, massages, and bed baths, assistance with accessing finances, material and social resources from the state such as grants, monitoring patients' diets,

fetching medication and monitoring adherence to treatment/medical advice, dealing with health personnel, bereavement counseling and provision of moral, spiritual and emotional support.

3. Unequal burden of AIDS caring responsibilities between women and men

As mentioned earlier, there is an unequal distribution of AIDS caring responsibilities between women and men. Women tend to carry out some of the responsibilities that are more hands-on, laborious, require more time and attention and thereby they incur greater time burdens. On the other hand, responsibilities performed by men,⁶ are usually those that have to do with physical strength and finances which can be accomplished in a shorter time. Also while the responsibilities carried out by men are limited to certain activities, those carried out by women cover a wide array of activities; usually the whole range. For instance while men who restrict their caring activities to the provision of financial and material assistance may not always provide such assistance because of absence, desertion, unemployment and other factors, women may have to provide financial support in addition to performing other activities (Akintola, 2008a). However, our understanding is blurred by the dearth of quantitative evidence on the distribution of specific caregiving responsibilities among individual family members providing care and those who do not⁷, men and women, children, adults and the elderly or among primary and secondary care providers (see Akintola, 2008a). Yet, the distribution of caring activities is dependent on household structure and living arrangements and therefore differences exist across different types of families. Most of the discussion about caring behaviour in other contexts focuses on traditional households⁸ which predominate worldwide. Yet the caring behaviour of men and women are markedly different in other 'vulnerable' households.

Data on men's participation in caring in the context of HIV/AIDS appears to have been shaped by the very cultural inhibitions that reduce men's participation in caring labour generally. Montgomery et al (2006) offer a useful explanation of the prevalent notions on men's participation in caring labor. They argue that while men take on some responsibilities in homes, these are rarely acknowledged or generally played down (Montgomery et al, 2006). These they attribute to prevailing norms regarding appropriate gender roles and responsibilities, which prevent communities from acknowledging men's positive contributions. Further, men who are willing to challenge traditional gender roles meet with derision and ridicule (Akintola, 2006a; Montgomery et al, 2006). This suggests that men receive a disincentive for performing responsibilities traditionally prescribed as that of women highlighting the need to acknowledge and nuance men's participation however small, and remove barriers to their greater involvement in caring (Montgomery et al, 2006).

a. Traditional households

A clearer understanding of the impact of the unequal distribution of AIDS caring responsibilities within traditional households⁹ could be appreciated by examining its impact on women and men's participation in the labour force (formal & informal), labour market (formal and informal) and other opportunities, as well as physical, emotional and social wellbeing. Caring impacts working caregivers and women are disproportionately affected because they carry a larger share of AIDS care responsibilities. Rajaraman et al (2008) compared working HIV-caregivers with non-HIV caregivers¹⁰ in Botswana and found that HIV-caregivers were significantly more likely to take leave from work for caregiving (53% vs. 39%) and for longer periods (13 vs 7.6 days). These leave days were also likely to be unpaid¹¹. Given that many caregivers work in casual jobs

and that many of those working in formal paid jobs are often not in permanent employment (Lindsey et al, 2003; Akintola, 2006a & b), they are frequently unable to take leave to provide care and often have to quit or lose their jobs involuntarily. HIV caregivers who take extended leave to care for their patients may lose their job and find it difficult to return to their jobs or find other jobs (Rajaraman et al 2006). Women who are self-employed especially in petty trading, tailoring and hairdressing also lose opportunities for earning an income (Akintola, 2004a). However, there is need for quantitative and qualitative studies to better understand the impact of caregiving on men and women in different kinds of work and different work situations

Agrarian economies predominate in most parts of Africa, particularly in the rural areas with women taking on a major role in farming activities participating in sowing, weeding and harvesting etc (Wiegiers et al, 2006). In principle men work assiduously on the farm and usually have time to relax during the day. Part of this time can potentially be used to assist with caring. On the other hand, women who also work hard on the farm during early mornings continue with reproductive work for the remainder of the day. In AIDS-affected families trade-offs often have to be made in the allocation of time between caring and farm work, and women are likely to give more attention to caring while men work on the farm (Nnko et al, 2000; Akintola, 2008a). In addition to the absence of women's labour on the farm because of caring at home, women are unable to receive support which could potentially come from men who may have to cover for women's absence on the farms and therefore have little time left to assist with other activities. Men may also be exhausted with the extra work that they have to do or use this as an excuse to avoid care work at home. Moreover, because there is little value attached to caring responsibilities as opposed to productive work, men who participate in market work and who provide finances for caring sometimes fail to acknowledge the difficulties experienced by women as a consequence of the additional care burdens they have to carry (Akintola, 2004a; Orner, 2006). This highlights the need to examine more closely the differential value attached to productive and reproductive work.

The focus on the impact of AIDS care on productive activities often masks the impact on social activities. AIDS caregivers experience stigma which may reduce their access to support from community members (Akintola, 2006; 2008; Mwinituo, 2006). Caring also takes up time meant for 'leisure' such that carers have little time for rest or respite or even to participate in social activities. These activities include attendance of meetings, social gatherings, religious activities and visiting family and friends, which help to improve emotional and social wellbeing. Social activities are not always distinct from economic activities in that issues relating to economic advancement and wellbeing are discussed during time meant for socializing. Inability to participate in these activities can therefore impact negatively on their physical and mental health as well as socio-economic well-being. Within the context of AIDS, 'leisure' is of great value since respite helps caregivers by preserving their sanity and ensuring they are able to continue with care work. In the context of AIDS, the value of care work extends beyond the amount of time spent in caring: average wage rate missed by the caregiver or the price/value of the 'outputs'/commodities produced (Bundlender, 2004) to include the other costs incurred while providing care. These include the cost to the caregiver of physical and mental strain and possible infection with TB/HIV. Given that women are more involved in personal care activities than men (Akintola, 2006a), they are more than men to miss out on social activities and to experience more

challenges to their physical and mental health than men who help with activities that are not directly related to personal care (Akintola, 2006a).

b. Non-traditional

Non-traditional households live in even more precarious circumstances than traditional households but are often not given proper attention in discussions about equal sharing highlighting the need to pay particular attention to them. Non-traditional households include households with PLWHA or orphans which are headed by single parents¹², orphans, and the elderly¹³ (Tarimo, 2004; Akintola, 2008a). While the challenges facing these households are similar to that of traditional households, their circumstances present unique needs beyond that of AIDS-affected households with both parents. Households headed by single parents are on the increase in Africa due to a number of reasons: deaths of household heads¹⁴ as a result of HIV/AIDS or other reasons, migration and migrant labor, non-marriage, divorce and separation and desertion by spouses. Gendered patterns of blame also exist where men blame women for HIV infection leading to separation or desertion (Akintola, 2006a). In principle, the absence of partners (male and female) may mean 1) that there is one adult labour less to share productive and reproductive responsibilities, which include emotional, physical and material/financial support 2) a lack of or poor access to potential social networks that may help mitigate the burden of care 3) social exclusion from spouses and social and economic groupings 4) lack of access to spouse's income or assets in the case of death of male spouse. Men and women's caring responsibilities cover physical care, emotional support and material support. The level of participation of men and women in these dimensions of care has received little research attention and could illuminate our understanding of the distribution of caring responsibilities in different types of families.

In agrarian communities where sexual division of labour is practiced, female-headed households affected by HIV/AIDS may be at greater risk of household food insecurity than male-headed households. A recent study comparing non-affected households with households with different structures¹⁵ affected by AIDS in Zambia showed that female and elderly headed households carry a greater burden of responsibilities than male-headed households because women's caring responsibilities prevent them from participating in agricultural activities that are typically carried out by men and also female-headed households have fewer male labour available to help with agricultural production. This implies that these households have to 'purchase' labour through exchange of goods such as beer and so forth (Esther Wiegers et al, 2006) Women who do not receive support for caregiving miss out on opportunities to grow their own food and be food secure. Wiegers et al (2006) show that in Zambia women heading households were less likely to participate in social activities and this excludes them from opportunities to learn about modern agricultural skills and improved seeds and technology. The authors also show that male-headed households with orphans had the highest total productive labor. However, although all affected households had more children participating in agricultural work than non-affected households, elderly headed households caring for orphans had more children involved in agricultural labor than all other types of households. While children's involvement can help increase food production and avert food crisis as well as reduce care burdens on the elderly, it affects children's study time, may cause absenteeism and withdrawal of children from school. Single male parents are likely to remarry earlier than single female parents and thus have access to female support. However, the negative impact of social norms is clearly seen in the impact on

single households headed by men when they do not re-marry because they may or may not enjoy support from female relatives. A lack of caring skills and experience as is common with men implies that men are not able to adequately care for their sick family members (Akintola, 2004b). Although as men they may work in the formal/ informal sectors or for subsistence, their ability to continue working may be compromised by their caring responsibilities especially where there are no other adults available. This leaves the entire household vulnerable to food insecurity and reduction in livelihoods options.

4. The role of home-based care

Informal caregiving refers to the provision of care by untrained people or those who receive informal or semi-formal training without expectation of immediate pecuniary reward (Akintola, 2008a)¹⁶. Informal caregiving takes place outside formal health facilities, in homes or within the community. Informal caregivers are mainly family members and they play a central role in the provision of care to PLWHAs in Africa (Akintola, 2008a; Rajaraman et al 2008). They are typically mothers, sisters, wives and female partners of the sick person and rarely fathers, brothers and husbands¹⁷. Although we do not have quantitative data on the proportion of people providing informal care across Africa, the magnitude of the epidemic and poor access to formal health care suggest that a high proportion of family members are providing or have provided care for a relative or community member. (Rajaraman et al 2008)

Given that families struggle to provide care for their ill members, home-based care in addition to addressing the capacity problems in the health sector is meant to mitigate the burden of health care on families through the provision of a continuum of care (WHO, 2002; Akintola, 2004b; Hall et al, 2006). The introduction of HBC helps mitigate the burden of AIDS on the health care system and AIDS-affected families as well as the other stakeholders-namely family and communities. Informal caregiving exerts considerable demands on families who, in the absence of outside assistance, find it difficult to cope. Home-based care organizations have stepped in to mitigate the burden of care on families. These comprise a variety of organizations from community-based organizations, faith-based organizations, non-governmental and non-profit organizations. Home-based care has been acclaimed by many international and donor organizations, governments as well as researchers as having many benefits. These include argument that allowing patients to receive care in a familiar environment improves the experience of dying and death (Uys, 2003; Akintola, 2008b). It has also been shown to assist in reducing stigma and discrimination as well as facilitate acceptance and disclosure of HIV status (Ncama, 2008). At the same time, informal caregiving has also been associated with negative physical and mental health outcomes as well as poor socio-economic outcomes. In particular, home-based care has been shown to increase caregivers' time-burdens thereby exacerbating poverty among previously poor caregivers (Hansen et al, 1998; Akintola, 2008a).

Individuals within communities assist others in caring for PLWHA. This is done voluntarily on an individual or sporadic basis or on a sustained on-going basis by joining home-based care organizations. It is the case that women predominate among those providing individual assistance to families as well as those who join voluntary groups. However, the involvement of volunteers on an on-going basis in care organizations necessitates a special focus on volunteering as a critical place that requires vigilance to ensure equal sharing of responsibilities. Home-based

care organizations depend almost entirely on unpaid volunteers who comprise a large proportion of their staff. They play a central role in the provision of care to people living with HIV/AIDS and therefore in mitigating the burden of AIDS on families. These volunteers are typically members of AIDS-affected communities who are recruited and trained by care organizations to assist and provide informal hands-on training for AIDS-affected families in carrying out care responsibilities in their communities. While volunteering is an activity that is practice worldwide in different settings, it takes on a very unique form and meaning in the context of HIV/AIDS in Africa in that volunteering has many of the characteristics of a full-time or part-time paid job in healthcare except that workers are not remunerated. In accordance with gender norms prescribing appropriate gender roles, most of those who volunteer are women since it has to do with caring. This coupled with the fact that volunteers spend an inordinate amount of time providing care with many walking on foot to their patients' homes (Campbell et al, 2005; Akintola, 2005) means that it has the potential to reduce women's participation in the labour force (Akintola, 2008a & c).

Some have argued that most of the volunteers are idle and that volunteering keeps them busy and assist communities mitigate the burden of care. However, this argument masks the fact that volunteers spend inordinate amount of time providing care and that most of them feel trapped in their role as caregivers finding it hard to quit (UNAIDS, 2000; Akintola, 2004a; Akintola, 2005; Akintola, 2008b). Volunteers help families reduce the burden of care on them (Blinkhoff et al, 2001; Hall et al, 2006; Esu-Williams, 2008) and in addition have to carry the burden of non-disclosure of patients' status (Akintola, 2006a; 2008b), carrying the burden of poverty and want among the patients they serve while at the same time coping with their own illness and having to defend their continued participation in a programme that takes up all their time, and sometimes money, without receiving any remuneration. (Blinkhoff et al, 2001; Akintola, 2006a; 2008a). Volunteers may also be at risk of violence and infection with TB/HIV (Lindsey et al, 2003; Akintola, 2006a). Regrettably, there is no sense of the number of people serving as volunteers across the continent (Akintola, 2008a). Further, there is usually an over-reliance on volunteers by family members and care organizations (Blinkhoff et al, 2001; Akintola, 2008a). Therefore the time spent by volunteers is usually well beyond what is normally required for volunteering in other contexts¹⁸. In the process volunteers miss potential opportunities for improving their lives through capacity building and human capital investments (Akintola, 2008a) that may come through self-development or development programmes. Although the training received could potentially be used to enter the labour market, it is not clear to what extent the skills acquired compensates for the value of opportunities missed (Akintola, 2008a). This has serious implications for poverty eradication and development policies and programmes.

Notwithstanding available evidence, the real positive and negative impacts as well as the gender dimensions of these impacts remains poorly researched and poorly understood. Although qualitative evidence suggest that home-based care exacerbates existing gender inequalities and disparities (Akintola, 2004b) and therefore the equal sharing of responsibilities between men and women, little quantitative evidence exist on this phenomenon.

5. State and other actors' provision of support

Individual support comes from immediate family members, extended family members (relatives), neighbours and friends. Since the epidemic started to impact communities, there has

been a notable increase in support received from family and community members. This has been variously referred to as social immunity provided by social safety nets (Mtika, 2001). However, with the epidemic showing little or no signs of abating, communities are finding it impossible to sustain support. This is due to dwindling material and financial resources in the face of a massive epidemic that affects almost everyone in high-prevalence communities. Despite declining financial and material support, families and communities still provide physical, emotional and moral support. Community level support comes from volunteers working with home-based care organizations (Akintola, 2004b) who represent the main source of support for HIV/AIDS affected families in Africa providing varying degrees of support depending on the level of resources available to them. Care organizations provide patients with medical care, food support to affected households in form of food parcels and support for subsistence food production and other income-generating activities.

Home-based care organizations receive funding and technical support mainly from international non-governmental organizations and development agencies. However, very few donor agencies fund caregiver stipends or salaries (Akintola, 2004b). Two exceptions are worth mentioning: 1) Swaziland pays a stipend/salary to caregivers who are mainly women with the help of the Global Fund¹⁹ (Hultman, 2004). The Steven Lewis Foundation also funds caregiver stipends/salaries as part of their policy (Diajate, 2008). The small number of agencies supporting caregiver remuneration highlights the need for the donor community to rethink their policies on funding support to care organizations and volunteers.

With respect to state support, this in theory should come both from the public health system as part of a continuum of care and from social protection policies. However, policies and implementation vary greatly across countries. In Uganda for instance, many government funded hospitals have an outreach arm which provides home-based care with support from their medical staff to affected communities and also to other care organizations though they also raise funds from international organizations to cover some of their costs (Akintola, 2004b). This is not the case in many other countries including South Africa where home-based care organizations are largely initiatives of faith-based organizations, churches, community-based organizations and NGOs (Akintola, 2004b). Although the state funds home-based care, the criteria for funding are not clear and only a few care organizations receive financial and material resources. Botswana funds home-based care as a continuation of hospital care but challenges include lack of transport for staff, problems with the referral system and remuneration. Indeed, most governments do not include the payment of any form of compensation to volunteers in their policies. However, some governments allow for stipends that cover volunteers' transport costs. A study of HBC organization in South Africa showed that about 56% of volunteers received some form of stipend meant to cover basic costs (CASE, 2005). In Botswana, remuneration of \$20 is given to volunteers to offset costs of transport but it is not enough to cover these costs (Shaibu, 2006). The result is that the continuum of care recommended by WHO (2002) are only achieved in pockets of 'model home-based care' programmes scattered across Africa. This means that large proportion of patients are unable to receive proper home-based care which includes medical care for opportunistic infections and this increases the potential that patients will be more dependent and require more time of their caregivers.

With respect to state support in the form of social protection, Botswana stands out as a country that provides food baskets for poor affected families. However, financial and human resource constraints and problems with service delivery and red tape impede access by many of the affected families (Shaibu 2006). In South Africa, the provision of an array of grants for different categories of 'vulnerable' groups helps provide support for HIV/AIDS affected households. Although not specifically targeted at affected households, these grants constitute the major, and in many instances, the only source of income for AIDS-affected families (Oni et al, 2002; Steinberg et al, 2002). This support can have a profound impact on the livelihoods of poor families but also on the gendered impact of home-based care. It can help reduce women's dependence on men. This is especially true for grants for carers such as child care grants and child-dependency grants, which are predominantly accessed by women. However, there remain a myriad of challenges in accessing support in these countries. In both these countries there is poor access to grants and food support (Lindsey et al, 2003; Shaibu 2006; Oni et al, 2002; Samson, 2002, Steinberg et al, 2002). Old age grants can also help reduce the misery of older people. However, there is concern about the disjuncture between the magnitude of need and the amount that is paid as grants. One major potential support that governments can provide is access to antiretroviral (ARV) therapy which considerably improves the health of persons living with AIDS (UNAIDS, 2008) and therefore reduces the need for them to be dependent on others. This can translate to a considerable reduction in the amount of time that caregivers need to provide care for patients and help free up time for women to perform other activities. However, despite efforts at expanding coverage to all (UNAIDS, 2008), ARV coverage in Africa remains low. As at end 2007, only about 31% of those who need treatment are receiving ARV treatment (UNAIDS, 2008).

6. Initiatives for promoting equal sharing between women and men

There are a number of initiatives to reduce the burden of caring on women and promote a more equal sharing of responsibilities in the context of HIV/AIDS but even fewer have been documented. These fall into different categories including programmatic efforts aimed directly at a more equal representation of men among family and volunteer caregivers as well as community level initiatives. These include drives or campaigns by home-based care organizations to recruit men. Unfortunately many of these initiatives are not available in the public sphere. However, there have been very few initiatives aimed at promoting greater participation of males in family caregiving but most are focused on increasing the number of males participating in volunteer care work.

Nonetheless, documented initiatives include that conducted by the population council in Zambia. This programme trained members of existing anti-AIDS clubs to provide care as an additional activity (Esu-Williams et al, 2002). Evaluation results showed that caregiving increased from 47% to 82% among males and from 41% to 78% among females (Esu-Williams et al, 2006). The greater increase among males could be attributed to a number of factors: 1) males needed less parental permission to participate in activities outside the home, 2) male activities are concentrated in the mornings leaving more time during the day while female domestic responsibilities are spread out throughout the day (Esu-Williams et al, 2002). In Goromonzi district of Zimbabwe, district councilors assisted in mobilizing men to form a group to share the caring responsibilities that was predominantly borne by women. They were provided with training and care kits to carry out their volunteer care work (Africare, 2007). A similar project

was initiated by Africare in Mutasa district of Zimbabwe. This ‘male empowerment’ project which aimed to break traditional barriers that prevented men from caring for PLWHA trained 120 men aged 20-65 to be volunteer caregivers. The project focused on expanding traditional notions about masculinity to include caring and supportive behaviour and also provided technical assistance, medical and material supplies. A common thread in mobilizing communities for greater male involvement in care is the enlistment of the assistance of traditional leaders, headmen and chiefs and this has been central to success (Esu-Williams et al, 2002; 2006). These initiatives have seen a remarkable increase in the proportion of men volunteering in home-based care. Of all these projects, only the one carried out by Horizon in Zambia evaluated quantitatively and qualitatively. The Africare project trained males to provide care for male clients because it was assumed that they will feel more comfortable with caring for males. Clearly there are barriers to involving men in family caregiving notable among them is that men express the desire for the time lost while volunteering to be compensated (Hall et al, 2006). Overall, these projects hope to build men’s interest in caregiving and achieve a ‘trickle down’ effect whereby volunteers will imbibe the culture of caring and provide care to family members as well.

7. Lessons learned and implications for policy

Home-based care for people with AIDS has increased the physical, emotional, financial and time burdens of families, with women carrying a disproportionate share of these burdens thereby increasing the unequal sharing of caring responsibilities among women and men. While all HIV/AIDS affected families bear the brunt of caring responsibilities, non-traditional families carry a heavier burden and need to receive particular attention in research and policy circles. AIDS is eroding social immunity afforded by social safety nets and the scale of the epidemic makes it unwise to expect that families and communities can cope without solid support from governments and international agencies. This study raises questions around how to deal with men and women’s mobility between traditional gender roles in the context of AIDS i.e. between productive and reproductive work. There is need to acknowledge the roles of men in caring for family members and remove barriers to their participation in care which include fears about stigmatization by community members, or discouragement from other men. Initiatives to increase male participation in care show that changing men or involving men in sharing the responsibilities of care work as volunteers is a process which is sometimes slow. Therefore there is the need to train children to participate in different roles within their families regardless of their sex. The need to care for the family and at the same time provide financial support appears to highlight the fact that one family member²⁰ may have to keep working for sustenance of livelihoods. While women’s equal participation in productive work and men’s participation in reproductive work are ideals that should occur simultaneously, adequate support is needed from governments to make this a reality. In this regard, governments need to create an atmosphere conducive for equal sharing, improve family/community wellbeing and increase productivity in the economy.

In general initiatives to mobilize adult men and youth have been positive and encouraging despite meeting with resistance initially. There is therefore a need to challenge dominant cultural norms and myths about masculinity and femininity. For instance the cultural belief that men must earn an income from their work serve as barriers to volunteerism. Exploring and redefining men’s masculinities to include caring as a sign of strength could have positive spin-offs within

families. While there is a need to mobilize men for greater participation in caring there is also need to resist policies that enable governments to transfer state responsibilities to poor and ill-equipped citizens. Also there is need to offset the income/time lost by men who are volunteering highlighting the point that volunteers (men and women) can not be expected to devote indefinite and inordinate amounts of time to caring for community members under the pretext of volunteering. One critical lesson learnt is that the value of time spent by carers is of great importance regardless of whether the carer is a youth, elderly, or adult man and woman in the productive age. It has far-reaching implications for work force participation, leisure, social well-being, education and human capital development and for the unequal sharing of responsibilities between men and women. This underscores the need to define what volunteerism means in the context of AIDS and for greater interventions from the State in reducing the burden of AIDS caring responsibilities on men and women.

8. Recommendations

- More research is needed to quantify different variables related to distribution of the various forms of caring responsibilities between men and women and to carefully study and nuance the experiences of men and women in different scenarios in the context of AIDS
- There is need to scientifically evaluate the success of male only volunteers vs female only volunteers, male only clients vs. female only clients vs mixed gender volunteers and clients and to track changes in male and female caring behaviour over time.
- Policy makers should set out plans and policies that will stop the blanket discharge of patients from public hospitals. This will ensure are discharged only after assessing the ability of their families to care for them
- Governments need to invest in human, financial and material resources for the provision of a functional continuum of care for AIDS patients. This will ensure that patients receive appropriate medical treatment and assist families reduce the time burdens associated with caring. Rapid scale-up of the ARVs could also reduce time burdens for families which they can spend on income earning activities.
- There is need for donor education on the importance of financial and material support for volunteer caregivers. A lack of understanding of the links between home-based care as is being practiced in many countries and unequal sharing of responsibilities between men and women will continue to undermine the efforts of volunteer caregivers and home-based care organizations and expand gender disparities. Advocacy is also needed at the national and international levels to influence donor organizations on funding policies.
- Home-based care programmes need consider gender perspectives in planning and implementation and to evaluate the gendered impacts as programmes are rolled out for feedback purposes
- Governments should provide social protection, such as food baskets, grants and access to free and functional health care as well as water and other basic social services that is accessible in poor rural areas, and education for the most vulnerable households irrespective of HIV/AIDS status. This can help reduce transport costs to and waiting time in hospitals and thereby mitigating the financial and time burdens of care.
- Policy-makers should consider mobilizing of social capital within communities. This can help engender or revive the culture of sharing which is particularly being eroded as a

result of the AIDS epidemic and economic difficulties. It could also facilitate caring, reduce stigma and encourage men to participate in carrying.

- Governments and donor agencies should pilot and evaluate various interventions aimed at compensating volunteers using various models of compensation viz: direct payment, human capital development and career pathing and eventual employment, income generating programmes etc
- International agencies should commission studies on the impact of AIDS morbidity and deaths on the sharing of caring responsibilities among men and women.
- Investment in labour saving technology and improved seeds can help mitigate the impact of AIDS on small holder agriculture.

REFERENCES

- Africare. (2007). Dedicated to care: Empowering Male caregivers in Zimbabwe. Available <http://www.africare.org/pint.php> (accessed June, 2008)
- Akintola, O. 2004a. Home-Based Care: A Gendered Analysis of Informal Care Giving for People with HIV/AIDS in A Semi-rural South African Setting. PhD diss. University of KwaZulu-Natal, Durban, South Africa.
- Akintola, O. 2004b. A Gendered Analysis of the Burden of Care on Family and Volunteer Caregivers in Uganda and South Africa. Health Economics and HIV/AIDS Research Division (HEARD), University of KwaZuluNatal, Durban, South Africa.
- Akintola, O.. 2005. Community Responses to HIV/AIDS: The Role of Volunteers in Home-based Care for People Living with HIV/AIDS in South Africa. Research Report for Centre for Civil Society, University of KwaZuluNatal, Durban, South Africa.
- Akintola, O. 2006a. "Gendered Home-based Care: More Trouble for the Troubled." *African Journal of AIDS Research* 5(3): 237–47.
- Akintola, O. 2008a. "Unpaid HIV/AIDS Care in Southern Africa: forms, context, and implications". *Feminist Economics* in press
- Akintola, O. 2008b. "Defying all odds: coping with the challenges of volunteer caregiving for patients with AIDS in South Africa" *Journal of Advanced Nursing* 63(4):357-365
- Akintola, O. 2008c. "Unpaid HIV/AIDS Care, Gender and Poverty: Exploring the links in Antonopoulos, R & Hirway, I. (eds.) Unpaid Work and the Economy : Gender, Time use and Poverty. Palgrave-McMillan. Forthcoming
- Blinkhoff, Petri, Esaya Bukanga, Brigitte Syamalevwe, and Glen Williams. 2001. *Under the Mupundu Tree: Volunteers in Home Care for People with HIV/AIDS and TB in Zambia Copperbelt*. London, UK: Strategies for Hope Series No 14, ActionAid.
- Budlender, Debbie. 2004. *Why Should We Care about Unpaid Care Work*. Harare, Zimbabwe: United Nations Development Fund for Women.
- Campbell, Catherine, Yugi Nair, Sibongile Maimane, and Zweni Sibiyi. 2005. "Home-based Carers: A Vital Resource for Effective ARV Roll-out in Rural Communities?" *AIDS Bulletin* 14(1) www.mrc.ac.za/aids/march2005/homebased.htm (accessed June 2006).
- CASE. 2005. *A National Evaluation of Home and Community Based Care*. Pretoria: The Community Agency for Social Enquiry.
- Diajhate, A. (2008) The AIDS Care Economy and the Burden on Women. Symposium at the XVII International AIDS Conference, August, Mexico City
- Esu-Williams, E, Motsepe, J., Chomba, M., and Chambeshi-Moyo., M. 2002. Mobilizing Young People for the Care and Support of People Living with HIV/AIDS in Zambia. Horizons Research Summary, Populations Council.
- Esu-Williams, E, Schenk, K., Geibel, S., Motsepe, J., Zulu, A., Bweupe, P., and Weiss, E.2006. "We Are No Longer Called Club Members but Caregivers': Involving Youth in HIV and AIDS Caregiving in Rural Zambia." *AIDS Care* 18(8): 888–94.

- Hall, C., Johnson, C. A., Flemming, W. O., Chipere, C. Matinhure, N, Myllynen, K., and Kadzik, M. 2006. *Man enough to care: Involving Men in Home-based Services for People Living With HIV/AIDS in Rural Zimbabwe* Washington DC:Africare
- Hansen, K., Woelk, G., Jackson, H., Kerkhoven, R., Manjonjori, N., Maramba, P., Mutambirwa, J, Ndimande, E., Vera, E.1998. "The Cost of Home-based Care for HIV/AIDS Patients in Zimbabwe." *AIDS Care* 10(6): 751–9.
- Hultman, T. 2004. "Swaziland: Unpaid Caregivers Ease Swaziland's Grim Struggle Against HIV/AIDS, *allafrica.com* May 7.
- Joint United Nations Programme on HIV/AIDS (UNAIDS). 2000. *Caring for Carers: Managing Stress in Those Who Care for People with HIV and AIDS*. Geneva: UNAIDS.
- Joint United Nations Programme on HIV/AIDS (UNAIDS). 2008. *Report on the Global AIDS Epidemic*. Geneva: UNAIDS.
- Lindsey, E., Hirschfeld, M. and Tlou., S. 2003. "Home-based Care in Botswana: Experiences of Older Women and Young Girls." *Health Care for Women International* 24(6): 486–501.
- Montgomery, .C. M., Hoosegood, V., Buisza, J., and Timaeus, I.M. 2006. "Men's involvement in the South African family: Engendering change in the AIDS era" *Social Science and Medicine* 62:2411-2419
- Mwinituo, P. 2006. Stigma associated with Ghanaian Caregivers of AIDS Patients. *Western Journal of Nursing Research* 28(4), 369-382.
- Ncama, B. 2008. "Community impact of HIV status disclosure through an integrated community home-based care programme" *African Journal of AIDS Research* 5(3):265-271
- Ngwenya, B. N. and Kgathi, D. L. 2006. "HIV/AIDS and access to water: A case study of home-based care in Ngamiland, Botswana". *Physics and Chemistry of the Earth* 31:669-680
- Nnko, S., Chiduo, B., Wilson, F. Msuya, W. and Mwaluko, G.. 2000. "Tanzania: AIDS Care - Learning from Experience." *Review of African Political Economy* 27(86): 547–57.
- Orner, P. 2006. "Psychosocial Impacts on Caregivers of People Living with AIDS." *AIDS Care* 18(3): 236–40.
- Pathfinder International. 2006. *Mapping of Community Home-Based Care Services in Five Regions of Tanzania Mainland*.
- Rajaraman, D., Russel, S., and Heymann, J.S. 2006. "HIV/AIDS, income loss and economic survival in Botswana". *AIDS Care* 18 (7):656-662
- Rajaraman, D., Earle, A., & Heymann, J.S. 2008. *Working HIV caregivers in Botswana: Spillover effects on work and family well-being*.

- Samson, Michael. 2002. "HIV/AIDS and Poverty in Households with Children Suffering from Malnutrition: The Role of Social Security in Mount Frere." *The South African Journal of Economics* 70(7): 1148–72.
- Shaibu, Sheila. 2006. "Community Home-based Care in a Rural Village: Challenges and Strategies." *Journal of Transcultural Nursing* 17(1): 89–94.
- Shisana, O., Hall, E., Muleke, K. R., Stoker, D. J., Scwabe, C., Colvin, M., Chauveau, J., Botha, C., Gumede, T., Fomundam, H., Shaikh, N., Rehle, T., Udjo, E., Gisselquist, D., (2002) *The Impact of HIV/AIDS on the Health Sector: National Survey of Health Personnel, Ambulatory and Hospitalised Patients and Health Facilities*. Pretoria, South African Department of Health.
- Steinberg, Malcolm, Saul Johnson, Gill Schierhout, and David Ndegwa. 2002. *Hitting Home: How Households Cope with the Impact of the HIV/AIDS Epidemic: A Survey of Households Affected by HIV/AIDS in South Africa*. Washington, DC: Henry J. Kaiser Family Foundation.
- Tarimo, Edith. 2004. *Assessing the Impact of HIV/AIDS on Informal Care: A Qualitative Study from an Urban Tanzanian Context*. M.Phil thesis, Centre for International Health, University of Bergen, Norway
- Tlou, Sheila. 2000. *The Girl Child and AIDS: the Impact of Secondary Care Giving on Rural Girls in Botswana*. Paper presented at the XIIIth International AIDS Conference, Durban, South Africa.
- Uys, L. R. 2003. "Aspects of the Care of People with HIV/AIDS in South Africa". *Public Health Nursing* 20(4), 271-280.
- Wieggers, Esther, John Curry, Alessandra Garbero, and John Hourihan. 2006: "Patterns of Vulnerability to AIDS Impacts in Zambian Households." *Development and Change* 37(5): 1073–92.
- WHO. 2002. *Community home-based care in resource-limited settings: A framework for action*. Geneva, World Health Organisation.

¹ In 2007, 75% of deaths due to AIDS occurred in sub-Saharan Africa, South Africa had a prevalence of 35% and 38% deaths in the same year.

² I have used the terms family and household interchangeably in this paper

³ This is particularly true for countries in Southern Africa which have the highest prevalence rates on the continent

⁴ Discussed in detail in a subsequent section

⁵ The concept of caring is used in the sense employed by feminist economists to include all activities carried out to improve the health and wellbeing of PLWHAs and also take care of PLWHAs in care providers responsibilities. This will include activities commonly referred to as care and support in the HIV/AIDS literature

⁶ Such as transportation to health facilities, ambulating and managing financial and legal affairs and dealing with medical personnel

⁷ Although it is rare to find a member of HIV/AIDS affected households not providing some form of care or the other, it happens all the same. This is more likely the case among vulnerable households discussed later

⁸ Defined as those with two spouses and usually headed by a man.

⁹ Refers to families that have both male and female spouses in the house.

¹⁰ The study did not indicate which types of work participants were involved in so we do not have sense of the proportion involved in formal or informal or subsistence employment

¹¹ The study used a purposive sample drawn from working people attending government clinics. Save for noting that there were significantly more women than men (79% vs. 21%) in the sample, the study did not perform an analysis to determine the gender differences in time allocated to care and the use of leave time among working caregivers.

¹² Heads of single parent households could be those in polygynous relationships with the spouse living elsewhere

¹³ Households headed by the elderly may also be skip-generation households

¹⁴ AIDS kills adults in their productive and reproductive age changing household structure such that an increasing number of households headed by women and these households are mainly composed of elderly and children.

(Wiegers et al, 2006)

¹⁵ Affected households with different structures included: female-headed households with PLWHA, female headed households with orphans, Male headed households with PLWHA and male headed households with orphans. (See Wiegers et al, 2006 for a fuller description)

¹⁶ Some form of informal caregiving are currently being paid this is a rare phenomenon

¹⁷ Men make important contributions by participating in caring this is discussed in a later section

¹⁸ Most volunteers spend at least 3 days a week while some work everyday. Most work for several years without remuneration.

¹⁹ Since its inception challenges have arisen regarding sustainability

²⁰ This is mostly possible in non-traditional households. Non-traditional households would require greater support from government.