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Towards equal sharing of AIDS caring responsibilities: Learning from Africa

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TOWARDS EQUAL SHARING OF AIDS CARING
RESPONSIBILITIES: LEARNING FROM AFRICA

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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 the burden of disease

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

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

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

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.

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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