



HEALTH ECONOMICS AND HIV/AIDS RESEARCH DIVISION

POLICY BRIEF

THE GENDERED BURDEN OF HOME-BASED CAREGIVING

Olagoke Akintola

August 2004

HEARD
University of KwaZulu-Natal
Durban
www.heard.org.za

Funded by:
United States Agency for International Development (USAID)



Introduction

In Africa, there has been a gradual shift from hospital-based care of people living with HIV/AIDS to home-based care. People living with HIV/AIDS often constitute a large proportion, if not majority of people seeking medical treatment at hospitals. Many hospitals do not have adequate resources to care for HIV patients. In response, hospitals and departments of health have implemented policies to promote home-based care of patients. However, in South Africa, the effectiveness of home-based care programmes is questionable, in the light of the research findings on which this Brief is based.

This Brief summarises comparative research conducted in South Africa and Uganda.¹ That research showed that home-based care (HBC) programmes in South Africa are inadequately developed compared to those in Uganda. Indeed, many HBC programmes and projects in South Africa reflect still a response of crisis management and, therefore, are unsustainable. Furthermore, they entrench gender inequalities, for due to the traditional roles of women, caregivers are usually women and young girls. This situation compounds the challenges faced by health services and NGOs concerned with developing home-based care policies and programmes.

Home-Based Care Programmes

In South Africa and Uganda, it is national government policy to promote home-based care. In both countries there are different organisations, mostly NGOs, offering different models of home-based care, ranging from home-visiting to home-based palliative care, to comprehensive treatment, care and support programmes. In South Africa, most of these care programmes rely on volunteers from the affected communities to carry out basic nursing and other caregiving activities in patients' homes. These volunteers are usually not paid or, in a few cases, paid small stipends for transport.

Home-based care has benefits for the person living with HIV/AIDS and for family members in the sense that it allows the sick person to be cared for in a familiar environment and affords them opportunity to prepare for their death and die with dignity at home. However, particularly in South Africa, hospitals usually discharge patients living with HIV/AIDS after a short admission period or do not admit them at all. The consequence in many cases is that patients are discharged to households whose family members have not received any form of training on how to care for people living with HIV/AIDS. Furthermore, the children, particularly girls, are often delegated caregiving tasks or, in cases of single parent households, have to be the primary caregivers.

NGO projects have thus stepped in to improve the situation, by setting up volunteer-based projects. The volunteers are usually members of the community who are otherwise unemployed, and who receive training to care for people in their homes. Volunteer-based home care projects stem from informal home-visiting activities initiated by religious congregations or concerned members. However, home care, be it by family members, concerned community members or volunteers is very stressful. The research study identified four major kinds of stress: physical stress, emotional and psychological stress, social stress, and economic stress.

¹ The full research report is available on HEARD's website (www.heard.org.za)

Physical Stress

Caregiving is very demanding and includes activities such as carrying, lifting and bathing of patients; staying awake at night to attend to patients who are in the terminal stages of their illness and cleaning those with frequent bouts of diarrhoea among other ailments. Caregiving goes beyond immediate bed care. Volunteers often take on household chores as well as assist with the care of the children. For volunteer caregivers, their work involves visiting several homes a day; in effect, working long hours and walking in the heat of day to assist. In sum, many of the volunteer caregivers become the main caregivers of the sick person and the work leads to stress related illnesses such as headaches and backache. They, like family caregivers, also face the risk of infection with TB and HIV because they often do not use protective devices when caring for the sick.

Emotional Stress

Caregivers usually have to provide care in trying conditions that contributes to feeling anxious and worrying about the deterioration in the physical state of their patients, which they are unable to arrest or reverse. They may also become involved with family members and worry about the economic conditions of the family and its struggles to secure assistance. Caregivers also find it emotionally stressful to bath sick family members such that some have to solicit for assistance from outside the family. Caregivers who are HIV positive, are constantly reminded of their own status and mortality. Caregivers report that this stress sometimes lead to insomnia, nightmares and the loss of libido.

Compounding this emotional stress, women caregivers usually do not usually voice their problems because socio-cultural norms make it improper for them to complain. Being a 'giver' they are compelled to maintain the stance of being stronger than the 'receiver'. Alternatively, they fear being seen to be insensitive to the plight of the sick. The danger is that this stress accumulates to the point of affecting their physical and mental health.

Social and Economic Stress

Caregiving is time consuming such that caregivers often do not have adequate time for rest and forego social activities such as religious gatherings and social meetings.

In some homes, the caregivers are the only breadwinners as well as heads of the households and, therefore, responsible for the provision of finances. However, family caregivers may be forced to relinquish jobs while caring for the sick. At the same time they have to contend with an increase in expenditure as a result of purchasing particular kinds of food for the sick, transporting them to health facilities, and the need for medicines. Volunteer caregivers suffer economic stress for many are unemployed and live in similar socio-economic conditions as the sick people they are caring for. In many instances they need support as much as the affected households they are assisting. An indicator of the levels of stress is that HBC programmes report high attrition rates amongst volunteers.

The burden of care is exacerbated in households headed by single mothers, because they do not have access to the support that should come from a husband and his family. In cases where husbands have died, his relatives may deny the widow access to family property thereby compounding her stress.

The Plight of Child Caregivers

Children often provide assistance to the primary adult caregivers and also assist in soliciting for food or material support. The situation at home can lead to lack of time for studying, even being withdrawn from schools to assist with caregiving. In homes where there is nobody else to care for the sick, children inevitably become the primary caregivers and often at a young age when they are ill-equipped mentally and physically to cope with the burden of caring for a dying mother or father or both, and in circumstances (particularly in South Africa) where adults do not talk openly about why their parents are ill.

Home-Based Care Models

Home-based care of HIV/AIDS patients entails varied activities and, notably, accumulation of demands on the caregiver. The experiences of different care organisations and the different models of care highlight these challenges. A home-based care project may start with caring for sick individual adults, but over time, has to confront needs such as child care services for sick parents, provision of material support for the affected families and, ultimately, orphan care services (e.g. payment of school fees, assistance with accessing social grants; providing housing for orphans; vocational training for those who have not attended schools; making funeral arrangements for their patients). Adapting to these demands raises new challenges of how to refine and expand an HBC project for it to be effective. The evidence from South Africa is that most care organisations do not have the resources to take on these services, such that the burden of trying to provide such assistance is carried in practice by the caregivers. Grandmothers, mothers, sisters, women friends and neighbours of the sick thus bear the actual burden of trying to meet the changing needs and demands of sick people and their families. Indeed, the research revealed that few care organisations in South Africa have taken into account the need to accommodate the changing needs and demands on their services over time.

In contrast, a striking feature of HBC programmes in Uganda is the professionalisation of care. The general pattern is for patients at home to be provided with specialised medical care as well as support home-visit services by teams that consist of medical doctors, nurses, other paramedics, and clerics for spiritual care. The HBC programmes use volunteers who identify sick people and in some cases provide basic care, but are themselves supported by the mobile teams of professionals. This is not to say that this system is manifest across the country. There are care organisations that operate different models of care, but there is substantive co-ordination and networking between hospitals, NGOs, religious sects and communities to override the limitations of individual organisations.

In essence, HBC programmes in Uganda are 'community-oriented' whereas in South Africa, they are 'community-based'. Comparison of programmes in the two countries

shows that South Africa is way behind Uganda with regard to understanding and meeting the challenges of providing home-based care.

POLICY RECOMMENDATIONS

- Many countries are signatories to the Millenium Development Plan. The third objective of the plan is to promote gender equality and empower women. However, home-based care in many communities in South Africa may prevent achievement of this goal. The use of girls, and in some cases boys, as primary or secondary caregivers affects their education. A starting point is to incorporate gender sensitive assessments in reviews of home-based care programmes.
- There is a need to review primary health care models in the face of HIV/AIDS; notably the role of the trained community health workers in relation to family and volunteer caregivers.
- There is a need to refine volunteer-based programmes – providing stipends and/or designing them to be steps for career development and formal job employment, in order to make it attractive and to reduce attrition rates.
- There is a need to recognise that the demands of affected families are varied and complex, are not restricted to basic nursing care and, most importantly, change over time. Therefore, home-based care programmes in South Africa need to be re-formulated; to become ‘community-oriented’ through introduction of professional support. The experience of Ugandan organisations shows that high level of networking and co-ordination can mitigate the limitations of capacity and resources of individual care organisations.
- In view of the psychological and emotional stress of caregiving, there is need for the introduction or revival of mental health programmes at the primary care level. Importantly, caregivers (including child caregivers) need psycho-social support.
- Finally, and perhaps fundamentally, governments and health departments need to acknowledge that that home-based care is not a cheap option. In South Africa, it appears to be appropriate, but the costs are hidden and defrayed onto the caregivers and communities who are least able to carry the burden. The current approach is unsustainable.