



HEALTH ECONOMICS AND HIV/AIDS RESEARCH DIVISION

**A GENDERED ANALYSIS OF THE BURDEN OF CARE ON
FAMILY AND VOLUNTEER CAREGIVERS IN UGANDA AND
SOUTH AFRICA.**

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EXECUTIVE SUMMARY

In Africa, there has been a gradual shift in the model of care of people living with HIV/AIDS from hospital care to home-based care. People living with HIV/AIDS often constitute a large, if not majority of people seeking medical treatment at hospitals. However, many hospitals do not have adequate staff and space to care for HIV patients. In response, hospitals, departments of health and even national governments, have implemented policies to promote home-based care of patients. However, particularly in South Africa, the effectiveness of home-based care programmes is questionable. Patients living with HIV/AIDS are often discharged from the hospitals after a short admission period or not admitted at all. Accordingly, this study was commissioned to understand the contexts in which home-based care and its variations is being provided in Uganda and South Africa, and to assess the gendered impacts that these programmes have on the members of the family and community as well as the organisations offering care for PLWHAs ('people living with HIV/AIDS'). This is intended to assist in designing policies and in the planning of home-based care programmes.

The study set six objectives to achieve its purpose:

- To describe the characteristics of family and volunteer community caregivers and the nature of the work they carry out;
- To describe the burden of caring for PLWHAs and determine whether it impacts differently on the health and welfare of male and female caregivers and if so, how?
- To describe the factors affecting men's involvement in the care of PLWHAs;
- To document the challenges and needs of family and volunteer community caregivers and care programmes;
- To describe the nature and magnitude of support available to volunteer and family caregivers from households members, community members, government and non-governmental agencies;
- To inform the design of policies and programmes that will mitigate the burden of care on families and communities.

This study made use of data from two main sources. The first was a rapid assessment of organisations offering home-based care as well as other forms of care to PLWHAs in South Africa and Uganda. To carry out the rapid assessment, various organisations offering home-based care in Uganda and South Africa were contacted. Interviews were conducted with programme staff, including heads of organisations, programme co-ordinators as well as doctors, nurses, volunteers and counsellors. These interviews were tape recorded and thereafter transcribed for analysis. Follow-up interviews were conducted with participants on the telephone. E-mails were also used to collect further information and to seek clarifications. The second main source of data was my recent ethnographic study (Akintola, 2004) among family and volunteer caregivers for PLWHAs in two semi-rural communities located 35 kms from Durban, South Africa. In addition, secondary data was also obtained from literature searches.

Models of care

The common thread in the development of home-based care models is the need to provide care for PLWHAs who otherwise would not be cared for adequately. Thus home-based care organisations are usually set up in response to the growing problem of care for PLWHAs. Care organisations are usually set up by hospitals, particularly Mission hospitals, to cope with the overstretching of health facilities; concerned individuals and groups of people some of whom may be infected with HIV or retired health professionals, and religious and international organisations.

Different care models have emerged that reflect the origin of the care organisations, their particular aims and objectives, and the actual needs of the PLWHAs:

- Community home-visiting care programmes which use volunteers (who are not paid) to recruit and provide patients with basic nursing care as well as spiritual and moral support.
- Home-based palliative care programmes that use hospitals and volunteers to recruit and refer patients to specialist nurses and doctors who visit homes regularly, using modern methods of pain control to relieve the pain of the patient.
- ‘Step down’ care with palliative care where patients are given care for severe opportunistic infections in stage 3 of illness and the dying are given palliative end-of life care.
- Tertiary out-patient care programmes which provide comprehensive rehabilitative and palliative outpatient care and receives referrals from hospitals, religious groups and local chiefs and other NGOs.
- Semi-comprehensive care programmes usually associated with home visiting by a team of medical personnel as well as counsellors and religious people.
- Comprehensive care programmes which provide services that include HIV/AIDS prevention, voluntary counselling and testing as well as treatment, care and support to PLWHAs.

The gendered burden of care

Caregiving is usually carried out by family members who serve as primary caregivers, and by community members who are recruited and trained to provide service as volunteer caregivers. Caregiving activities include provision of physical and emotional support to patients, and work 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 debilitations. Family members and volunteers often take on household chores and assist with the care of the children of the sick people. For volunteer caregivers, their work involves transferring knowledge by training family members on how to care for the sick, visiting several homes a day, working long hours and walking in heat of day to assist. Many volunteer caregivers become the primary caregivers of the sick person.

Caregiving is very demanding for the family and volunteer caregivers alike. The work leads to physical stress, emotional and psychological stress, social and economic stress. Caregivers experience physical stress related symptoms such as headaches, backaches, and general body weakness and fatigue. Some of the family members also face the risk of

infection with TB because of frequent close contact with patients and also risk of HIV infection because they do not use protective devices when caring for the sick. Emotional and psychological stress manifests in tearfulness, sleeplessness, nightmares, feelings of guilt, helplessness and hopelessness about the imminent and frequent deaths of patients, and tearfulness. Caregivers experience social stress as a result of alienation from friends and other social activities and also strains in caregiver-care recipient relationship. The economic burden of caring for the sick sometimes fall on the caregivers who often have to grapple with increased cost of living, decreased income from loss of jobs/job opportunities, transport to health facilities and transport of dead/funeral costs.

The burden of caring for the sick weighs disproportionately on women not only because they are the main providers of care in homes, but also because many have lost their male partners or have never been married and, therefore, have to bear alone the financial costs of caring for self and sick family members. Furthermore, men rarely assist with caregiving because they are usually involved in formal or informal activities to earn an income for the family. Some however, deliberately shirk their responsibilities. When men do assist (e.g. bathing patients, cleaning and treating pressure sores), women caregivers often feel uncomfortable as opposed to when men assist with hospital visits and arranging transport for the sick.

Conclusions

This study shows that many families are not in a position to offer home-based care without undermining the wellbeing of family members. The needs of affected households are enormous, and increase and become more complex over time. This highlights the need for substantial investment in the care of people living with HIV/AIDS and their families. In addition, the study raises questions around the adequacy and sustainability of many of the care models that make use of volunteer caregivers. There is a need to recognise the effects that caregiving has on women and that home-based care is not a simple, easy answer to the demand for extensive care programmes for PLWHA. This study shows that it is necessary to rethink existing care models in order not to exacerbate poverty and existing gender inequalities among affected families and communities.

LIST OF ABBREVIATIONS

AWOFS	AIDS Widows and Orphans Support
CADACC	Catholic Archdiocese of Durban AIDS Care Commission
CBOs	Community Based Organisations
CHW	Community Health Worker
COC	Community Outreach Centre
FCG	Family caregiver
HBC	Home-Based Care
IGAs	Income Generating Activities
NGOs	Non-governmental organisations
PLWHAs	People living with HIV/AIDS.
STI	Sexually transmitted infection
TASO	The AIDS Support Organisation
TB	Tuberculosis
VCG	Volunteer caregiver

Chapter One

Introduction and Background

In most countries in sub-Saharan Africa, policy changes in the area of health care have had tremendous implications for the care of people living with HIV/AIDS (PLWHAs). In countries that have been severely affected by the pandemic, HIV/AIDS patients form a large proportion of the patients that are cared for daily by formal health facilities. Many hospitals are unable to cope with the deluge of patients that come to them. For example, in 1986, 60% of patients admitted to the medical wards of Kitovu Hospital in Masaka, Uganda were HIV-positive and many more people in nearby rural areas were not able to access any medical treatment for HIV-related conditions (Kaleeba et al, 2000). In South Africa more than half of admissions to the medical wards of King Edward VIII Hospital in Durban in 1998 were HIV-related (Colvin, 2000). In an attempt to address the problem of overcrowding of formal health facilities and the lack of sufficient capacity to care for PLWHAs in formal health facilities, some African countries have started to promote home-based care as an innovative, suitable and cost effective way of providing care for PLWHAs.

In South Africa and Uganda, home-based care has become a national priority health policy. As a result of this policy, there has been increased 'de-hospitalisation' of patients. This coupled with the wish of many patients to die at home and the cost of transport to hospitals has led to a shift from hospital care to home-based care for PLWHAs. The shift to home-based care has resulted in an increase in the number of non-governmental organisations (NGOs) offering home care services and other non-formal kinds of care for PLWHAs. Most of these community care programmes thrive on the magnanimity and extraordinary sacrifice of family members and volunteers who are increasingly being relied on to mitigate the impact of HIV/AIDS on families and communities. They indeed constitute a valuable resource to affected households, communities and the health care system.

Findings from previous studies indicate that home care programmes, if properly planned, can relieve the pressure that the care of HIV/AIDS patients has on formal health care facilities (Nsutebu, 2001, Uys, 2002). There is also evidence to suggest that such programmes have clear health, social and economic benefits for the patients, families and communities (Akintola, 2004). Despite these advantages and the wide acclaim of home and community care as a favourable alternative or supplement to hospital care, we know little about the burden that falls to the people that give care to the sick and dying let alone the broader implications of home-based care.

Accordingly, this study was commissioned to understand the contexts in which home-based care as well as other forms of care for PLWHAs is being provided in Uganda and South Africa, and to assess the gendered impacts that such programmes have on the members of the family and community who give such care as well as on the organisations

offering care for PLWHAs. This is intended to assist in designing policies and in the planning of home-based care programmes.

In order to achieve this purpose, this study set six objectives as follows:

- To describe the characteristics of family and volunteer community caregivers and the nature of the work they carry out.
- To describe the burden of caring for PLWHAs and determine whether it impacts differently on the health and welfare of male and female caregivers and if so, how?
- To describe the factors affecting men's involvement in the care of PLWHAs
- To document the challenges and needs of family and volunteer community caregivers and care programmes
- To describe the nature and magnitude of support available to volunteer and family caregivers from households members, community members, government and non-governmental agencies
- To inform the design of policies and programmes that will mitigate the burden of care on families and communities

Chapter Two

METHODS

This study makes use of data from two main sources. The first source of data is a rapid assessment of organisations offering home-based care as well as other forms of care to PLWHAs in South Africa and Uganda. In order to carry out the rapid assessment, various organisations offering home-based care in Uganda and South Africa were contacted. Organisations visited in Uganda included Mengo home care, AIDS Widows and Orphans Family Support, St Frances Hospital, Nsambya, Meeting Point, Namuwongo Kampala, The AIDS Support Organisation in Entebbe, and The AIDS Support Organisation, (Mulago hospital) in Kampala. Information was also collected from the National Association of Traditional Healers, Kampala. Three organisations participated in the rapid assessment in South Africa. These are the Community Outreach Centre of St Mary's Hospital, Mairanhill, Sinosizo home-based care programme located on the periphery of Durban in Amazimtoti and the Dream Centre in Pinetown. Interviews were conducted with programme staff, which included heads of the organisations as well as doctors, nurses, volunteers and counsellors. These interviews were tape recorded and thereafter transcribed for analysis. Follow-up interviews were conducted with participants on the telephone. E-mails were also used to collect further information and to seek clarifications.

The second main source of data is my recent ethnographic study (Akintola, 2004) among family and volunteer caregivers for PLWHAs in two semi-rural communities located 35 kms from Durban, South Africa. In addition, secondary data was also obtained from literature searches. Other sources of data include peer-reviewed articles and abstracts as well as unpublished research reports. Literature searches were conducted using search engines such as Medline, Sabinet, Pubmed and NISC. Internet searches were also conducted using the Google and Yahoo search engines to obtain information from unpublished reports and articles that was not available in peer-reviewed journals. The Uganda AIDS Commission library was visited and discussions were held with the head of the social and economic sector of the Commission.

The value of this comparative assessment is that it enables reflection on the previous ethnographic data that I collected, which was focussed mainly on the activities of volunteer caregivers from one care organisation as well as family caregivers. This study is intended to give further insights into the challenges of home-based care and also to see the broader relevance of my previous study.

Chapter Three

Origins and development of home-based care in South Africa and Uganda

In Uganda, home-based care for PLWHAs started many years before South Africa. This is due, in part to the fact that Uganda was one of the earliest countries to be ravaged by the epidemic long before South Africa where HIV/AIDS began to pose a problem only in the mid 90s. The first AIDS cases were confirmed in Uganda in 1984. Although the first AIDS case in South Africa was recorded in 1982, the epidemic of HIV/AIDS did not start until about a decade after the epidemic in Uganda.

Although the reasons for starting home-based care programmes vary among the home-based care organisations that participated in the study, the common thread was the need to provide care for PLWHAs who otherwise would not be cared for adequately. Home-based care organisations are usually set up by individuals or groups in response to the growing problem of care for PLWHAs. Some of the organisations are often started spontaneously with little or no planning but just to meet the needs of the PLWHAs and their families who need care and support (Department of Social Development, 2002). To that extent, therefore, there is a similarity in the origins of most of the home-based care organisations in both South Africa and Uganda. My previous study, Akintola (2004), showed that the reasons for volunteering among community members caring for PLWHAs in the community outreach programme (COC) of St Mary's Hospital were varied and complex. However, altruism and the need to respond to a disastrous situation were the most common reasons given by the volunteer caregivers for enrolling in COC's home-based care programme. The lack of government response to the problem of people dying in large numbers had prompted many of the community members to enrol as volunteers in the home-based care programme.

The care organisations that participated in this study have four major origins. The most common are those in response to the problem of overstretching of hospitals and lack of capacity to care for PLWHAs. These care programmes are started mainly by hospitals that record high numbers of HIV/AIDS patients and are finding it difficult to cope with caring for them. Such programmes are then initiated as a semi-autonomous arm of the hospital. Most of the home-based care organisations in this category were started by Mission Hospitals. For example, St Francis hospital Nsambya and Kitovu Catholic Hospital in Masaka district were the first organisations to develop home-based care in the late 80s. The programmes were started because of the deluge of patients infected with HIV/AIDS that came to these health facilities. There were also no bed spaces to keep the patients in the hospitals. The hospitals therefore decided to start a care programme to cater for such patients at home in order to reduce the pressure on the hospital workers. In 1987, Kitovu Hospital started the first Mobile Home Care Programme in Africa for people living with HIV/AIDS and their families (Kaleeba et al, 2000). Thereafter many church-based hospitals and health centres in Uganda started similar home care programmes (Kaleeba et al, 2000).

Similarly, in South Africa the COC of St Mary's Hospital was started when nurses noticed that PLWHAs discharged from the hospital had to be readmitted to the hospital because they did not receive adequate care at home (Akintola, 2004). Many of these patients did not have people caring for them at home while in other cases the primary caregiver had to go to work leaving the sick person to care for himself or herself. In cases where family members were available to give care, many of them did not have the requisite knowledge and skills to provide care. Some were also reluctant to care because they were afraid they could get infected (Akintola, 2004).

The second group of care organisations are those that were started by concerned individuals or groups of people. The AIDS Support Organisation (TASO), Uganda was formed in 1987 by a group of 16 volunteers, including 12 people with HIV/AIDS in Kampala (Kaleeba et al, 2000). The organisation was formed to support people living with HIV/AIDS. Meeting Point Kampala was started by a group of Christians, most of whom were members of the Catholic Church. The organisation was started as a response to the problems encountered by Christians infected with HIV/AIDS. At present its clientele has gone beyond Christians to members of other communities. It is registered as an NGO located in Namuwongo village, Kampala. A similar organisation is to be found in the Vaal area of South Africa where HIV infected patients are usually discharged to go home because of the shortage of hospital beds. Vaal AIDS home-based care was started by four women in response to the harassment that was usually meted out to PLWHAs in the Vaal community (Department of Social Welfare, 2002:123).

The third group of care organisations are those started formally by religious organisations. Two examples of these were included in the study. Sinosizo home-based care was started in 1995 by the Catholic Archdiocese of Durban AIDS Care Commission (CADACC) to cater for PLWHAs. Sinosizo is a Zulu word for 'we help'. The vision of Sinosizo is to work for change so that communities in under-resourced areas in the Durban Metropolitan Area are able to take responsibility for the care, support and acceptance of people affected by HIV/AIDS, TB and STI's. The second organisation, the Dream Centre, was started by a Pentecostal Church known as the New Germany Bible Fellowship located in Pinetown. The Dream Centre was started as a result of a vision that was given to the leader of the Fellowship by God to start a place to care for PLWHAs. In response to this vision the church started by approaching different people who assisted in facilitating the establishment of the Centre. The Centre through the assistance of the department of housing was able to purchase a large property for a reduced price where it operates its 250-bed facility. The mission of the Dream Centre is to restore hope and dignity to sufferers of disease by providing effective medical treatment, compassionate healthcare and relief of pain in the Spirit of Christ. This mission gives boost to the Centre as a Christian organisation.

The fourth group consists of those started by international organisations. Examples are The Mildmay Centre in Uganda, which was set up by Mildmay International after an invitation from the Uganda AIDS Commission on behalf of the Ugandan government. Although the Mildmay Centre is non-denominational, Mildmay International is a Christian organisation. Hospice Uganda is another example of an international care

organisation. Hospice Uganda is an affiliate of Hospice Africa and it specialises in palliative care and support for people with terminal diseases.

Most of the organisations visited in Uganda started and operated in the capital city, Kampala, before opening branches in semi-rural and rural areas. This is in contrast to the experience in South Africa where the pattern is that care organisations start and are located in semi-rural or rural communities. There are very few examples of care organisations that started in cities in South Africa, and even where they do the target groups are usually people from the communities in the outskirts of the city. It is worth noting, however, that in both South Africa and Uganda, care organisations seem to be located in the areas most affected by the epidemic. Many Ugandan care organisations have their headquarters located in Kampala partly because the city and its environs are among the most affected areas in the country. It should be noted also that in Uganda, some of the care organisations such as Hospice Uganda, TASO and St Francis Hospital have smaller outreach centres in the semi-rural and rural areas for instance, Hospice Uganda has recently opened offices in Hoima and Mbarara.

Chapter Four

CAREGIVING FOR PLWHAs/AIDS ORPHANS AND VULNERABLE CHILDREN

Many of the care organisations use models of care that reflect their origins. Different care models reflect particular aims and objectives and actual needs of PLWHAs in different settings. I outline the different models below. However, as I indicate later, a key finding of the research was that the organisations have had to, or are under pressure to, elaborate their original models in response to the needs of the people they serve and, more generally, the changing nature of needs of populations infected and affected by HIV/AIDS over time.

1. Community home-visiting care programmes

This model is possibly the most common in rural and semi-rural areas in South Africa. An organisation using this model was the focus of my previous study (Akintola, 2004). Two examples are the Community Outreach Centre of St Mary's Hospital, Marian Hill and the Sinosizo home-based care, Amazimtoti, both in KwaZulu-Natal.

Volunteers are the backbone in this model of home care. Volunteers are recruited from the communities and trained in basic nursing care. They visit homes of sick people to offer basic nursing services, counselling, health education, nutrition monitoring and also psychosocial support. Basic nursing activities carried out include the cleaning of wounds, treating pressure sores, mouth care, turning the patient, assisting with toileting, and assistance with visiting health facilities and the procurement of medication from the health facilities. They also teach the families basic skills on how to grow farm vegetable gardens for subsistence. Volunteers also train family members to become the primary caregivers. An important component of this model of care in both Uganda and South Africa is the provision by volunteers of moral and spiritual support to the sick. They also provide directly observed treatment (DOTS) for those who are on TB medication. The volunteers do not prescribe or administer any drugs, but refer serious cases to the health facilities¹. Many of these home care programmes have had to include the care of patients with other chronic diseases in the programmes in order to avoid the being stigmatised by community members².

Some of these home care programmes have social workers that take care of the needs of the patients such as distribution of food parcels and assistance in securing welfare benefits, by liaising with or referral to welfare officers. Sinosizo has a social worker that helps needy households prepare their papers for presentation to the social welfare office and this has improved success rates. As at the time of the interviews, reportedly 85% of the patients have been assisted to do their paper work. On the other hand, COC uses counsellors and volunteers to prepare papers for their patients. They are thereafter referred to social workers to follow up. Most of these care organisations have only a few

¹ Similarly, UNAIDS (2000) notes that these programmes provide very little medical care for the sick.

² The issue of stigma is discussed further in chapter six

care professionals and most of them are mainly involved in training and supervision of volunteers.

In principle, volunteers are supposed to assist family caregivers. However, in many instances, volunteers have had to carry most of the burden of caring for the sick. In many homes where there is nobody to look after the sick, volunteers often become overloaded with caring activities to the extent that many of them become the primary caregivers of these patients. They assist with cleaning the homes of their patients, washing, cooking and doing other household chores. Some volunteers also spend their own money to provide food for their patients or transport them to the health facilities. In addition some volunteers often have to organise for the burials of their dead patients³.

2. Home-Based Palliative Care.

Palliative care is the total active care of someone with an incurable illness, where the control of pain and other physical, psychological, emotional and spiritual needs are paramount and where the goal is an improved quality of life (WHO, 2002)⁴. Hospice Uganda provides palliative care to patients with cancer and people living with HIV/AIDS. The purpose is to give such patients good end-of-life care. The need for palliative care in Uganda arises from the fact that there is an increase in the incidence of cancers associated with HIV/AIDS-known as AIDS-defining cancers and the fact that only 0.5% of PLWHAs in Uganda have access to antiretroviral therapy (Kikule, 2002). Hospice Uganda located in Makindye, Kampala and Kitovu Mobile Home Care are examples of a programmes providing home-based palliative care. Care providers at Hospice Uganda use modern methods of pain and symptom control for patients whose pain is difficult to control⁵. The purpose is to make certain that terminally ill patients are able to die in peace and dignity without pain. Doctors and nurses use oral morphine to reduce the pain and suffering of patients that often occur in the advanced stages of illness and they give other medications to improve patient's quality of life⁶. Uganda is the first and only African country so far that has made palliative care for people in the terminal stages of AIDS and cancer part of its national health plan, and morphine has been provided free by government since 2002 (Lancet, 2003). The powdered morphine is made into dilute solutions that the patients can take orally.

At Hospice Uganda, home care is given to patients by a home care team comprising a doctor, a nurse and the driver. The team visits the homes of people living with HIV/AIDS

³ This is a point to which I shall return later in chapter five, which deals with the burden of care

⁴Palliative care has also been described as the combinations of active and compassionate long-term therapies intended to comfort and support individuals and families living with a life threatening illness. Such care strives to meet the physical, psychological, social and spiritual needs of ill people. It is usually given to people who are terminally ill and emphasises helping people to make the most of each day and maintaining a sense of hope. The control of pain is a central goal of palliative care and enables people to die in peace, with dignity and in keeping with their own wishes.

⁵ A study by Kikule (2002) in Tororo, Uganda indicates that the main perceived need of people who are dying of cancer and AIDS is pain relief. In addition, Merriman and Heller (2002) note that many care programmes that claim they are offering palliative in Africa neither prioritise the control of pain through the use of morphine nor provide appropriate end-of-life care.

⁶ The hospice claims to have achieved a 95% relief of pain in 95% of patients (also see Merriman and Heller, 2002).

and those suffering from cancer within 20 km radius of the hospice in Kampala on other days of the week. Specialist nursing services are given to the patients in addition to counselling from the team as well as spiritual support. Patients are also allowed to come into the premises once a week for day care where they are taken care of by the medical teams and volunteers. Outpatient clinics are also held at the hospice, which also receives referrals from hospitals. In addition, the hospice recently began using trained volunteers known as 'vigilantes' to identify and refer patients to the hospice. Kitovu Mobile Home Care also runs a palliative care programme separate from that of Hospice Uganda in the largely rural districts of Masaka, Rakai and Sembabule (Lancet, 2003). The programme, one of the first of its kind in Africa, started by recruiting volunteer Community Workers, who became the frontline implementers of HIV/AIDS care, support and prevention activities within their own communities (Kaleeba et al, 2000: 30). They visit AIDS-affected families to provide counselling, information and health education and also to assess the need for social and economic support. Community Workers are supervised by hospital-based teams comprising three nurse-counsellors and a driver. The teams travel five days a week to provide medical and nursing care to sick people who gather at fixed meeting points, which may be a church, under a tree, community hall or outside someone's house (Kaleeba et al, 2000). 'Vigilantes' assist in organising these clinics for patients who are still mobile and their carers. Pastoral care also forms part of the activities of the Mobile Programme. Hospice Uganda collects a contribution of 5,000Shs (US\$ 2.5) per week towards the total cost of 22,000 (US\$ 11) per week for care independent of the number of visits and medications.

The initial aim of the Mobile Programme was to support families by improving their knowledge to be able to care for their sick relatives. However, the programme was confronted with the needs of HIV/AIDS affected households such as food, blankets, soap, housing, school fees, uniforms and scholastic materials. Response to these needs has formed a part of the work of the Mobile Programme since 1988.

3. Tertiary outpatient care programmes

Only one programme, the Mildmay Centre Uganda, falls into this category. This Centre offers comprehensive rehabilitative and palliative outpatient care for PLWHAs at all stages of the disease. The Mildmay Centre Uganda opened in September 1998 as a result of an agreement between the government of Uganda and Mildmay International based in the United Kingdom. The Centre is a not-for profit specialist Centre receiving referrals from other hospitals in Uganda, local chiefs and religious groups. The centre has a full diagnostic laboratory and pharmacy. Patients are not allowed to buy drugs from outside and all drugs prescribed are dispensed by pharmacists in the centre. A team of professionals, which include occupational therapists, physiotherapists, aromatherapy specialists, pharmacists, nutritionists and counsellors, offer unique outpatient services to clients through the use of a holistic approach to care. A pastoral team consisting of a Catholic priest, an Imam and a Pastor for other Christian denominations take care of the spiritual needs of the patients. The Mildmay Centre also operates day care services for children infected with HIV/AIDS. All patients who come to the Centre have already been tested and certified HIV-positive. Although Mildmay does not carry out home-based care, follow up visits are conducted occasionally to patients' homes. Clinics operate four

days a week. Patient attendances at the centre are now running at 1,400 per month and growing at 24 per cent each year. The centre operates a cost sharing service where patients are required to pay a subsidised fee treatment. Children and needy patients, however, are treated free of charge. The centre has also established support groups for PLWHAs who attend the centre, most of whom are involved in income generating activities. Mildmay has recorded remarkable results using this care model. Many of the patients who are being treated for opportunistic infections report significant improvement in their health. I had the opportunity of having a group discussion with 4 women who were members of the support group and were HIV infected and were all bed-ridden when they started to receive treatment at the Mildmay Centre. They were in good health at the time of the discussion; and all reported significant improvement in their health, and the emotional and psychological support given to them had significantly improved their outlook in life.

4. Step-down care with palliative care

This is a rare model of care. Only one example of this programme was found among the participating care organisations. The Dream Centre in Pinetown, South Africa is the only organisation operating this model of care for PLWHAs in South Africa. It receives referrals from collaborating hospitals in Durban and environs. This model fills a niche in the continuum of care. It is a care programme that falls in between home-based care and hospital care. The motivation for this model of care is that many patients when discharged from hospitals are too sick to be cared for at home. Patients are recruited into the centre only through referrals from hospitals and clinics. Patients cared for in this model fall into two categories. The first category are patients with full-blown AIDS, in stage 3 of infection who might die soon if they are not given intensive medical treatment. The second category comprises patients who have reached stage 4 of infection and whose death is irreversible even with proper medical treatment⁷. Patients in stage four are given palliative care. Patients are treated by doctors and nurses in the institution until they have sufficiently recovered to be accepted into the home-based care system before being discharged. It is the centre's policy that patients be discharged only to home-based care organizations. Accordingly, the centre is developing partnerships with home-based care organizations across the city of Durban and environs. A home-based care network was launched recently, which is called Sisizabonke home based care network. The network is made up of several home-based care organizations operating in rural and semi-rural areas of KwaZuluNatal.

The Dream Centre has a full-time counsellor who takes care of the psychological and emotional needs of the patients. In addition, a full-time social worker that helps prepare paper work for grants for the patients. The Centre believes that the social workers presence has been instrumental to the success rates recorded in the area of grants. Many of the patients have been able to secure grants as a result of this. In many cases, burial of patients who die at the Dream Centre presents challenges. The centre has had challenges coping with the problem of relatives abandoning their sick patients and this has prompted

⁷ The US Centre for Disease Control classifies people living with AIDS into three stages according to the severity of illness. Stage 1: asymptomatic HIV, Stage 2: symptomatic HIV and Stage C: full blown AIDS. However, the Dream Centre classifies those in the later stages of stage 3 as being in stage 4 of infection.

the Centre to have a collaborative agreement with funeral parlours that assist by burying the dead at a reduced rate.

5. Semi-comprehensive programmes

These programmes offer a wide variety of services to PLWHAs that include nursing and medical care, counselling, health education, and material and financial support. Semi-comprehensive programmes are usually affiliated to a hospital. This is the most common model of care run by hospitals in Uganda. Examples of such model are the Home-based care project of St Francis hospital, Nsambya, Mengo Home Care, Mengo, and Meeting Point Kampala. Home care services are carried out by a team of medical personnel usually comprising a doctor, nurse, counsellor and a driver who conduct regular visits to HIV/AIDS affected homes. The teams visit patients in their homes regularly and refer cases to their hospitals. In a few cases, where there is a partnership between these care organisations and other NGOs who run home-based care projects, the medical teams visit homes of people in the care programmes of NGOs that are affiliated to them. For example, Medical personnel from Nsambya hospital visit patients in the home care programme of Meeting Point, Kampala. This model also has programmes for AIDS orphans and support income generating projects for them. A significant feature of this model is that volunteers are not the major providers of care. They assist in identifying ill people, refer cases to the home hospitals and during home visits, assist with house chores. All the organisations practicing this model also provide spiritual and moral support to patients. They typically have a clergy, commonly a pastor, on the home care team. For example, Mengo Hospital Home care Project has a pastor on the home care team.

5. Comprehensive Care Programmes:

This is a model that aims to provide treatment, care and support as well as services that include HIV/AIDS prevention, voluntary counselling and testing as well as care and support to people living with HIV/AIDS. Only one programme, TASO, Uganda, falls into this category. TASO is one of the largest non-governmental organisations of HIV-infected and affected people in that country. It provides HIV/AIDS counselling, social support, medical and nursing care at seven centres. The seven centres located in seven different districts in Uganda are affiliated to district hospitals in the country. TASO also operates day care centres and provides HIV/AIDS education, nutritional support, and support for vulnerable children in all its seven Centres. It also conducts screening and treatment of TB and STIs for its patients. Home-based care programmes provide medical and counselling services to very ill patients, who are unable to come to the clinics, in their homes. TASO is also involved in the training of counsellors, community workers and care providers and advocacy and networking. In addition, TASO trains care providers from other care organisations in counselling and care of PLWHAs.

In all TASO centres, supplementary community based outreach clinics are operated at least thrice a month as a way of reaching individuals who cannot use the centre based service due to the high costs of transport and the state of their health. An outreach care service is conducted at an agreed upon locality in the community where a mobile team of medical personnel, counsellors attend to the sick. The organisation has collaborative agreement with Mildmay who provide training for its medical and paramedical staff in

clinical management of TB. They also collaborate with private institutions who provide X-ray services for their clients at a fee.

A South African example of semi-comprehensive care model is the one offered by the South African Hospice Association, which developed the Integrated Community-Based Care Model (ICHC) at the South Coast Hospice in KwaZuluNatal in 1997-98. The model has been implemented by the South African Hospice Association (SAHA) in seven pilot sites in five provinces across South Africa. The model links four major partners (PLWHAs and their families, community caregivers, hospices, as well as clinics and hospitals) in a continuum of care that delivers quality care from diagnosis to death and to bereavement (Uys, 2001).

New Demand: Different Models

As indicated there is an inevitable demand for different types of services and sometimes more than the care organisations can provide. A common problem reported by most home-based care organisations is that they have had to deal with the problem of care for orphans left by people who die of HIV/AIDS related illnesses. Orphan care has therefore become by default part of the services offered by most of these organisations. This demand creates new and particular challenges for the organisations. An additional and taxing challenge is providing care and support not only for orphans but also for the many children who are themselves infected with HIV. At Meeting Point Kampala, for example, about 4 per cent of the total orphan population being cared for is HIV-positive. Similarly in South Africa, the Orphan and Vulnerable Children's Programme of the COC of St Mary's hospital are looking after over 1,000 children who have lost both parents to HIV/AIDS-related illnesses.

Care organisations have responded to the problem of providing care and support for orphans in a variety of ways as I outline below:

a. Caring for orphans in parents' homes

This is a common care arrangement for orphans in both Uganda and South Africa. After the death of both parents, children are left in their parent's homes. In some cases, relatives are brought in to care for the orphans. In other cases, members of the community who serve as volunteers visit the children occasionally to ensure that they are coping and also assist in resolving conflicts. Care providers at Sinosizo realised that their own home-based care programme, which did not initially include an orphan or child care support component was incomplete. It was usual for home-based care volunteers to stop visiting families once their patient died. This meant that children were left to care for themselves. The effect is the same as loss of both parents. The problem of orphans is more in single parent households as there are sometimes no relatives to care for the children of the sick person when he/she dies. These problems led Sinosizo to start a project for the care and support of orphans and vulnerable children⁸.

⁸ This was an addition to the existing home-based treatment and care programme that already included infected children. Similar programmes were started by COC of St Mary's Hospital.

The orphan care programme of Sinosizo takes care of orphans who are left in child-headed households and also assists surviving parents. The orphans are given assistance in form of financial and material support. They are also given psychosocial support. There are currently twenty-five child-headed households covered by the programme.

b. Foster care

Foster care is an orthodox solution to the challenges of providing care for orphans. It is common practice in South Africa and Uganda, not only in cases where surviving children have no relatives to care for them, but also because it has been recorded that members of communities (even surviving relatives), upon the death of the parent(s) strip the household asset and take no responsibility for the children (Kaleeba et al, 2000). Care providers and people living with HIV/AIDS who participated in this study also corroborated this assertion. This they attributed to the tradition/customs that say children cannot own a property.

Such families are supported by some care organisations such as Meeting Point, Kampala, AIDS Widows and Orphans, Kampala, and in South Africa, the Orphan and Vulnerable children's programme of the COC and Sinosizo. Meeting Point operates different kinds of foster care. The most common model is to bring orphans together in a boarding facility. The facility is referred to as foster house and is located on the property of the Meeting Point. There are two elderly people serving as their foster parents, living with them full time in the house and attending to their needs.

One other kind of foster care model operated by Meeting Point is to keep orphans with foster parents who are not related to the children, but live in close proximity to the Meeting Point offices in Namuwongo district of Kampala. Meeting Point provides school fees, school uniforms as well as food items for all the children in this programme. The AIDS Widows and Orphan Support Programme operates a programme whereby orphans are placed with responsible members of the community who serve as foster parents. Both organisations support these foster families with food and other material things.

c. School-based orphan care

The COC of St Mary's Hospital has developed a care programme focussing on orphans and vulnerable children in both primary and secondary schools. The programme takes care of the psychosocial needs of orphans. Care providers meet orphans in selected schools once a week after school hours for about 2 hours in the school premises. Lunch is provided for the children during the meetings, which usually opens with songs and prayers. They are also taught life skills, which include conflict resolutions skills and building self-esteem among others. The programme also organises outings for the children. Children who need assistance with food and other material needs are referred to the home-based care programme to be followed up by volunteers. They are given food parcels once in three weeks and the volunteers also assist them with preparing their papers for securing grants. Some of orphans whose problems cannot be dealt with by the OVC programme are referred to the Children Rights Centre in Durban.

Reportedly, the major problems of the programme are that they cannot cover the many schools who have orphans and want to participate in the programme.

Introducing orphan care and support projects, however, brings new challenges. Meeting Point, Kampala, for example, supports child-headed households and pay for the electricity bills, rent, food and other requirements of such orphans. AIDS Widows and Orphan Support, Kampala in addition to supporting orphans in their parents' homes have built houses for some of them and they also cover their bills.

The education of orphans who are left by HIV/AIDS is a serious issue that many care organisations have had to address. Organisations such as the AIDS Widows and Orphans Support project at Nsambya Hospital and Meeting Point, Kampala support the education of orphans by soliciting funds for them from corporate and individual donors. Support is provided for orphans to attend primary, secondary and tertiary institutions depending on the level of support received from donors. When asked about the criteria used to determine the level of education to which orphans are supported, NGOs disclosed that most of them are sponsored to secondary school level after which they are sent into vocational training; a few are lucky to find people, mostly foreign donors, who are interested in them and provide funds for them to be supported to tertiary level. For instance, the AIDS Widows and Orphans Family Support, Nsambya, Uganda, in addition to the funding support received for the programme from donors, also seeks sponsorship from individual sponsors for the education of orphans. The organisation operates what they call the 'God-father' programme whereby pictures of orphans are taken and sent to a coordinator of the orphans' adoption project in Italy. These pictures are used to raise funding for the orphans from individual donors who adopt orphans. Similarly, funding is raised for antiretroviral treatment for orphans and adults.

It is common for child care organisations in Uganda to enrol orphans living in child headed households in schools with boarding houses so as to make sure that they can concentrate on their school work since it is difficult to concentrate on school work while living all alone. AIDS Widows and Orphans Support, Kampala and Meeting Point have enrolled some of their orphans in boarding houses. The need to provide this sort of assistance has been recognised in South Africa, but has not been acted upon. For instance, care providers at the Orphan and Vulnerable Children's Project of St Mary's Hospital indicated the need to place some of the orphans who have no relatives to care for them in foster care homes, but that they lack the resources to carry this out. Sinosiso home-based care programme assists children of volunteers to buy uniforms. They have also been successful with securing exemptions for volunteers' children and orphans not to pay school fees, citing their work to the community as a basis for the applications.

Care providers at Sinosiso told me that one difficulty of caring for orphans was that they could not provide daily supervision. Consequently, in the absence of a 'parental figure' the children were often undisciplined and were truant from schools. This experience highlights the challenges that arise as organisations attempt to serve the needs of those infected and affected by HIV/AIDS via HBC. Consequently, initial models and operations have to be refined further as outlined below.

There are always new challenges in caring for orphan children. Meeting Point, Kampala pays trainers to provide the vocational training for orphans and infected people on the premises of the organisation at Namuwongo, Kampala. Meeting Point has introduced vocational training for children who have had no formal education as well as those who have dropped out of school due to the illness or death of their parents and have missed some years. Children who drop out in primary school have missed between 8-10 years of education and are now about 19 and 20 years old. Such children cannot be admitted into secondary schools and, therefore, are sent to vocation schools. Some orphans are also sent to these schools because the care organisation is unable to secure sponsorship for them. Vocations learnt include tailoring, shoe making, hairdressing, welding.

The aim of this project is to enable the children to acquire skills to get jobs to support themselves as well as their younger siblings. However, in reality, these projects have mixed success. At the AIDS Widows and Orphans Support, boys who chose to learn welding, motor mechanics and carpentry have been very successful and have started their own businesses. However, most of the girls who chose to learn tailoring have not been as successful. Some of the boys who dropped out of school also have problems because they are not able to compete with their colleagues who completed their education before enrolling in the vocations. Many of them acquire motor mechanic skills, but are not able to pass exams and obtain formal certifications as mechanics. On the whole men have been more successful than women.

Loans are given to them to start business after their vocational training. AWOFS Nsambya's experience is that most of the grantees are able to pay back the loans because the organisation gives strict and close monitoring to the beneficiaries. Meeting Point, Kampala assist orphans who have graduated from their tailoring programmes by giving them contracts to sew school uniforms for other orphans who are being sponsored to school. AWOFS also assist PLWHAs in starting income generating projects. The same is true of support groups for PLWHAs at Mildmay Centre.

Another common thread among care organisations is the need to respond to the poverty among their clients. Income generating activities have been initiated by most of the care organisations. Family members of the sick as well as the sick people are trained in income generating skills. In KwaZulu-Natal, for instance, many of the organisations teach families basic gardening skills and provide seeds to plant crops for sustenance. Sinosizo has developed a partnership with the faculty of Agriculture, University of KwaZulu-Natal who assist in training volunteers and affected family members. In Uganda, AWOFS Nasambya encourages PLWHAs to start income generating projects. They provide loans and supervision in order to ensure that the loans are repaid. The loans are given to groups of PLWHAs who are able to submit good funding proposals.

Conclusion

The various models of care fill different needs of PLWHA and their families. The experiences of different care organisations shows that that they have had to constantly

adapt to the meet the varied needs and changing demands of the PLWHAs and affected families.

In broad terms, a home-based care project may start with caring for sick individual adults, but over time, has to incorporate family and orphan care services. The provision of material support for the affected families and orphan children is also a major service rendered by care organisations. They have also had to provide housing for orphans, facilitate their education and vocational training. Some care organisations have also had to take make funeral arrangements for their patients. Adapting to these demands raises new challenges of how to refine and expand them in order to be effective.

It is worth noting however that a major feature of most of the care organisations in Uganda is the professionalisation of care. Patients are provided with specialised medical care as well as support services by a team of medical professionals that usually consist of medical doctors, nurses, and other paramedics as well as religious personnel. Hence we see an attempt to provide a continuum of care among Ugandan care organisations, which is usually achieved by creating networks and partnership with other care organisations. In these models, volunteers identify sick people and, in some cases, provide basic care but they are also supported by mobile teams who provide medical and supportive services. Accordingly, these organisations charge their patients subsidized fees in order to recover some of their costs and also create a special fund for the treatment of the poor.

In contrast, the common models in South Africa use volunteers to provide basic nursing care as well as moral and spiritual care. Volunteers cannot administer any drugs and medical care is usually obtained in the health facilities because medical personnel rarely visit PLWHAs in their homes. In essence, many care models in Uganda operate community-oriented care in contrast to the community-based care commonly operated in South Africa. One of the common threads through all the models of care rendered, however, is the provision of spiritual and moral support for patients. In achieving this most of care organisations use prayers and counselling. Many of the organisations in Uganda have clergies who provide spiritual guidance and support for the patients.

In sum, home-based care for PLWHAs in South Africa is simplistic in conception and in practice. This is not to denigrate the efforts of care organisations in South Africa, but they are only beginning to confront the challenges of providing home-based care and have yet to learn from the experiences of organisations in Uganda.

Chapter Five

THE BURDEN OF CARE

Home-based care programmes generally focus on encouraging family members to care for sick and or training members of communities to be volunteer caregivers. However, there is very little research in Africa on experiences of these caregivers. Here I summarise results of my previous study (Akintola, 2004). I make some comparisons to information obtained in Uganda. However, it must be noted that I had largely secondary sources in Uganda.

The caregivers described in this study are those who do not receive remuneration for their work. Very few studies in Africa have sought to understand the characteristics of this category of caregivers except for mentioning that most of the caregivers are women and girls. In this study, as in my previous work (Akintola, 2004) I distinguish family caregivers (FCGs) as the main caregivers, and usually members of the family, of the sick person. Volunteer caregivers (VCGs) are members of a community who have received some form of training on the care of PLWHAs and who provide care beyond their own households and families. In reality, individuals may be both FCGs and VCGs. Those who receive training to become volunteer caregivers may also have family members who require care.

My previous study examined the socio-demographic characteristics of family and volunteer caregivers in a semi-rural setting in South Africa. That study revealed a preponderance of women as caregivers of PLWHAs. Only one of the twenty-one family caregivers was a man. Most of them were sisters (6) of the patient, followed by mothers (5). The others were neighbours (5), daughters (2), a grandmother and friend. Notably one of the daughters giving care was a 10-year old child. The other daughter was 33 years old who had 2 children of her own. The only male FCG was a cousin of the patient. Nine of the 21 family caregivers had received some training by the COC of St Mary's Hospital as volunteers while the remaining twelve had not received any training in home-based care. Most of them had between 7 to 12 years of education.

Likewise the socio-demographic characteristics of the VCGs were similar to that of the family caregivers. Only one of the twenty volunteer caregivers was a male, the others were females; all but 2 of them were unmarried, one was divorced and all of them had at least one child. Most of them had between 7-12 years of education, though 2 were University graduates.

My previous study showed a common pattern in the socio-economic status of both the family and volunteer caregivers. Only three FCGs were employed. Two were domestic workers and their incomes ranged from R15-R20 (\$2.5-\$3.0) per day.⁹ The third was a hairdresser. One of the FCGs was a student. The others did not have any particular kind of employment or source of income. More generally in the sample, most families were poor. Using local knowledge and perceptions of wealth, which included, kind of house,

⁹ The average rate of exchange at the time of the study was US\$1: R6.50.

possession of piped borne water and latrines, ability to afford decent meals among others, seven of the HIV/AIDS affected families were judged to be of very poor socio-economic status, 7 to be poor, 6 to be moderate and 1 to be well off by local standards.

Four of the volunteer caregivers were employed: 2 worked as temporary domestic workers, one worked as a hairdresser, one a petty trader and fourth a tailor. Similarly the socio-economic status of the volunteers was like the ones of the family caregivers.

Volunteers cited the lack of employment as one of the reasons why they joined the volunteer programme. Some indicated that they did not want to stay at home 'doing nothing'. In view of this however, many of them hoped for a future reward from the COC or from the government. Many of them stated that 'perhaps someday the government will give us something for our labour'.

The activities carried out by caregivers in my previous study were varied:

- Provision of moral and spiritual support to the patient.
- Provision of basic nursing care, which included wound care, massaging the patient and mouth care, guidance and support for adequate nutrition.
- Provision of physical care, which included lifting and turning patients and managing incontinence, assisting the patient in walking, bathing, feeding and dressing.
- General assistance with household chores, monitoring drug adherence, transport to health facilities.
- Assistance in dealing with medical personnel as well as managing the affairs of the sick person, including general care of the children of the sick person.

In other words, the results of the study showed that caregiving is very demanding irrespective of any training that caregivers may receive. The variety of care is largely a function of changing needs and demands of sick people and their families. As the patients' condition deteriorates, so the tasks change. Initially, caregivers only gave general assistance, but later they had to give nursing care, assisting children and ongoing spiritual and moral support. In the case of VCGs and occasionally for FCGs, caregiving extends beyond death of patient to bereavement support and assistance to surviving household members, particularly children.

The cumulative demands made on caregivers lead to considerable stress for caregivers. I identified, in my previous study (Akintola, 2004) four major kinds of stress:

- 1) Physical stress,
- 2) Psychological and emotional stress,
- 3) Economic stress.
- 4) Social stress

Physical Stress

Physical stress usually comes from lifting and supporting patients, bathing patients, doing household chores and other duties for the sick person and, for some of the volunteer caregivers, walking long distances in the sun to patient's houses was physically stressful. Symptoms reported by caregivers include sudden and recurring headaches as well as general body ache (backache being the most common complaint). Caregivers were also exposed to the risk of infection with TB while carrying out intimate personal care activities such as bathing, turning the patients and assistance with incontinence. Some family caregivers were also at risk of infection with HIV because they did not use protective devices while caring for their family members. Some of them did not know for sure that the care recipient was HIV-positive. Others refused to use protective devices because they felt that it would imply that they did not love the sick person.

Psychological and emotional stress

The signs and symptoms of psychological and emotional stress included tearfulness, worry, anxiety, nightmares and insomnia. Worry and anxiety were often a result of the inability of the caregiver to come to terms with the diagnoses of HIV/AIDS for the person they were caring for and the inevitability of that person's death (often under trying conditions). More specifically, one finding was that bathing sick family members was often psychologically, as much as physically stressful and some caregivers reported that they preferred to solicit assistance from friends who were not related to them or the sick person. Furthermore, the frequent multiple deaths witnessed by caregivers particularly volunteers working in a community was also a source of emotional stress. Finally, a particularly significant cause of stress was being HIV-positive and also a caregiver.

An additional source of emotional and psychological stress for volunteers is the attitude of community members. Interviews with providers at Sinosizo home care programme revealed that people in the community usually raise questions about the competence of volunteers whose patients die frequently. This puts pressure on volunteers who, at the same time, have to cope with their own grief.

Economic Stress

Economic stress was ever present for most caregivers for they often had to provide care for a family in straightened circumstances resulting from illness of the sick breadwinner. My study (Akintola, 2004) indicated five major factors responsible for economic stress:

1. Reduction in household income mainly due to the PLWHA or caregiver losing their jobs.
2. Increase in the cost of daily living incurred with the need to purchase particular or special food for the sick person.
3. Cost of purchasing medicine and paying for other medical related expenses also presents financial burden on affected households.
4. Financial costs are also incurred for transporting the sick to the clinics and the hospitals, and the dead to their hometowns for burial.
5. Care of children of the deceased is a subsequent cost in cases where a family takes them in to their homes.

More generally, the costs of funerals were a financial drain on the surviving family members. It is not uncommon in KwaZuluNatal and more broadly in South Africa, for families to provide food and drinks for at least 100 or more people at a funeral and pay for buses to transport mourners in addition to the burial costs.¹⁰ As a result of this impoverishment, many affected households in the rural and semi-rural areas of South Africa cannot afford to pay for the funerals of their family members. In my recent interviews, a care provider at Sinosizo home care project, stated that volunteers have now resorted to taking their patients to the hospitals just before they die in order to abandon them there with no contact address of the relatives. The reason for this is that if the patient dies in the hospital they might be given a paupers burial by the government¹¹. However, the volunteers would also inform the family members who could then keep going to the morgue every week to check when their relative would be buried and attend the funeral. In contrast, in the communities served by COC, it was common for families to transport ill relatives back to their villages just before they died in order to avoid the prohibitive cost of transporting them when they were dead (Akintola, 2004).

My earlier study (Akintola 2004) study of semi-rural South Africa showed that the caregiver was usually the breadwinner in many of the affected families. This may be due to the fact that the original breadwinner had died or was ill. In cases where the caregiver was in paid employment, caregiving disrupted the caregivers' time resulting in absenteeism at work. For those who were in self-employment, caregiving competed with the time for earning.

In South Africa, most caregivers were not employed. Caregiving, therefore, was an activity that reduced opportunities to look for work or earn an income through informal sector. In Uganda, in contrast, where many households grow crops for household consumption as a norm, caregiving (and illness of a family member) in addition, reduces the capacity of caregivers to grow their own food.

Although none of the participants in my previous study revealed that they sold any property as a result of the sickness of their family member, this is probably a reflection of the level of poverty in the households that participated in the study. Many did not have much property of value and that could be sold to offset debts or meet obligations for the care of their family members¹². Some of them resorted to borrowing from neighbours and friends in order to meet basic needs. Others reached an agreement with their landlords to owe them money. The issue of poverty was also a pervasive theme in the discussions with care providers and HIV positive people in Uganda. However, many of those interviewed in Uganda disclosed that selling of property was a common response to the

¹⁰ Studies conducted in Swaziland, a country that shares borders with South Africa, by Desmond et al (2004) shows that funeral costs including death announcement in media, gravesite, catering, coffin and undertakers could range between US\$280-US\$560.

¹¹ In South Africa, pauper's burials are given for unclaimed bodies in mass graves. The cost is paid for by the government.

¹² In contrast, Steinberg et al (2002) studied the impact of HIV/AIDS in selected provinces in South Africa and found that AIDS affected households were spending up to a third of their income on private medical care and some families had to sell off their properties to pay for their bills.

need for money to care for the sick and feed the family. People living with HIV/AIDS are not treated free by many of the care organisations in Uganda, as noted previously. Antiretrovirals are expensive; therefore patients on antiretrovirals have to pay more than those receiving treatment for opportunistic infections¹³. Many people accessing ARVs have to sell their properties including their land to secure antiretroviral drugs. Unfortunately, many are not able to continue when their source of income is used up.

I (Akintola, 2004) indicated that poverty was so rife among families and volunteers that they expressed bitterness with the government and the care programmes. Some of them believed that the lack of food in affected households undermined the home care programme to the extent that 'nothing is gained by either the volunteers or the sick people from home-based care'. One volunteer caregiver said 'the patient is hungry and we are hungry too and there will be no communication between the two of us'.

Although care programmes give incentives to volunteers, these are not enough to meet their basic needs. Some of the incentives are, end of year stipends and assistance with treatment for those HIV positive caregivers who cannot afford it. Volunteers in the study disclosed that they needed to receive some stipend to cover at least some of their own material needs. Volunteers' financial problems are compounded by the fact that some of them have to spend their money to transport patients to the hospital or to buy food or other materials for them. Some of the patients also put pressure on them by asking them what they brought for them and demanding unrealistic material things when they go on home visits.

Social Stress

Social stress usually results from isolation and discrimination against the affected family that can occur in communities as a result of widespread stigma surrounding HIV/AIDS. For instance, caregivers who feel compelled not to disclose the HIV status of their patients have to work effectively in silence and amidst lies about their work. Also they are constrained with regard to asking for assistance from neighbours or other members of the community. Caregivers in my previous study also reported stress arising from the lack of appreciation and outbursts of anger from those they were caring for.

Findings from previous study were corroborated in this study. For instance, Ugandan organisations highlighted the physical burden of care. A graphic illustration was a recounting of caring for individuals in the terminal stages of illness. A common symptom at this stage of illness is frequent and recurring bouts of diarrhoea, which means that the caregiver often has to stay awake all night assisting the person to the toilet or changing diapers and being available to provide for any other needs. Those needs can include taking the sick to a health facility. In rural areas in Uganda this can mean transporting individuals 10-15kms to a health facility. This creates enormous stress for the patients

¹³ At Mildmay, patients on ARVs pay \$15 as opposed to \$3 for those accessing drugs for opportunistic infections. However, at Nsambya, Mildmay, and Meeting Point, some patients get sponsorship from individual or corporate donors and are accessing ARVs. The organisations have a waiting list of those who need ARVs and this is what they use to determine who gets it.

and the caregivers who have to support or sometimes physically carry them. In some cases patients are carried on bicycles or in wheel chairs to the health facilities.

The comparative research in Uganda also highlighted migration as a factor contributing to the physical as well as emotional stress encountered by volunteer caregivers and care organisations. In Uganda, people have migrated from war torn countries bordering Uganda such as Sudan, Rwanda, the democratic Republic of Congo, as well as from the northern part of the country which is being ravaged by war. Immigrants tend to settle in Kampala in search of jobs and many have secured jobs in factories and intermarried among themselves. Reportedly, most of them live in poor conditions in one- room shacks and when they get infected there is usually nobody to take care of them; and when they die, it is difficult to trace their families¹⁴.

Nonetheless, it seems that care organisations in Uganda as well as in South Africa have yet to pay adequate attention to stress and the resulting health problems that volunteer caregivers experience. One representative of a care organisation, when asked to describe volunteer's health problems, stated that they did not have any. However, other caregivers in Uganda corroborated those in South Africa that volunteers often keep quiet about the physical and health problems they suffer. Reluctance to report these problems is due in part to socio-cultural values whereby the volunteers are regarded as being physically and emotionally strong because of their work. In KwaZulu-Natal, in Zulu culture, givers are seen as stronger than receivers. Furthermore, volunteers do not want the sponsors of their training or programme officials to perceive them as incompetent. In addition, an underlying reason for keeping quiet is personal guilt about possibly appearing to be insensitive to the plight of the sick person.

The psychological and emotional stress that volunteers experience is due in part to the experience of HIV/AIDS in their own families. A counsellor in one of the care organisations in KwaZulu-Natal stated that more than half of their volunteers report HIV/AIDS-related problems in their own families. TASO is an example of an organisation that has recognised that stress could have a negative effect on their staff members¹⁵.

As in my previous study, the comparative research also showed that the psychological and emotional stress experienced by caregivers is a result of witnessing death and dying. The clustering of HIV/AIDS in families was found to be largely responsible for caregivers witnessing too many deaths. In such families, caregivers have to care for more than one person with illness and eventually witness the death of all of them one after the other. I encountered this sad scenario (Akintola, 2004) in the case of a 68 year-old woman who had to care for 4 of her children, two of whom died within three months of each other. However, the dynamics of family life that lie behind this clustering are different between South Africa and Uganda. In Uganda, informants indicated that it was common for girls to marry the husbands of their dead sisters if they felt that he was

¹⁴ Although the problem of migration discussed creates additional physical and emotional burden for the caregivers, it also relates to stigma and shame as will be discussed in Chapter Six.

¹⁵ This issue is discussed further in Chapter Nine as one of the lessons learnt by care organisations

wealthy enough and capable of providing for their needs. They also noted that a lot of infected widows and widowers remarry which serves to spread the infection within the family. In addition, care providers reported that it was common for stepfathers to have sexual relationships with their stepdaughters. When the men die they leave infected widows and children. The widows may also remarry infecting their new sexual partners. Also the practice of polygamy spreads HIV/AIDS and causes a clustering of AIDS related illness.

In contrast in South Africa, clustering of HIV infection is mainly due to living the arrangements. For example, it is common to find young 'black' adolescent girls bearing children without being married (Preston-Whyte, 1993; Hosegood and Preston-Whyte, 2001) and by different men (Akintola, 2004). These single parents typically lived with their own parents in multigenerational households, which comprised about a quarter of households that participated in the study. In other words, there is a high probability that one or more members of a household could be infected.

In Uganda and South Africa, children in the HIV/AIDS affected households are also exposed to physical and psychological stress, which they are least equipped to cope with. At Sinosizo in KwaZuluNatal, programme staff recounted the problems that ensue with their decision not to train children to be caregivers. According to her, volunteer caregivers usually train the elderly and adults in the affected homes and the children are usually sent out when this training is being done. However, the children actually care for the sick when the volunteers leave despite the fact that they do not have any training. The problems encountered by children caregivers are myriad. Patients in the terminal stages of the disease who are bedridden need to be turned from time to time to prevent them from having bedsores, but children find it difficult to do this task because of their size. Although people have said that such children could solicit help from their friends, many parents would not want their own children to assist because of fear of contagion.

The problem of children serving as primary caregivers is brought about in many cases because hospitals do not always ask who are the caregivers before discharging patients. What then happens is that the patients do not have anyone to look after them except their children. A Sinosizo staff member described a situation where a single parent was discharged and she had only a 7 year-old child who was living with her. The boy was so distraught that he asked health care providers 'will I have to change my mother's nappy'? Such is the nature of the burden that is imposed on families who are least prepared to care for PLWHAs. Some care providers also recounted stories of children found sitting near their deceased mothers without knowing it. In Uganda, children who have lost their parents encounter similar problems, as they have to care for their younger siblings who are infected with HIV.

As indicated in Chapter Four, most care programmes in South Africa rely primarily on volunteers as the main providers of care for the sick. The volunteers are not paid and this is also a source of stress and disillusionment. The lack of payment combined with the stresses experienced by volunteers has led to high attrition rates for such volunteers.

Conclusion

The comparative study highlighted the burden of caring for PLWHAs. The burden falls disproportionately on women and leads to enormous physical and emotional stress. Despite the presence of potential stressors however, physical and emotional and psychological health problems were not readily reported by both family and volunteer caregivers largely because of social-cultural factors that underlie the care of the sick in the communities. In many instances, children, mostly girls, serve as both primary and secondary caregivers and this has negative implications for their mental health as well as their education.

Volunteer caregivers also have to contend with the physical and emotional stress that results from caring for sick community members as well as their own sick kin. The emotional burden of caring for a sick family member and, at the same time, caring for other community members is so heavy on the volunteers that some have to solicit for assistance from other volunteers. Some of them who are HIV positive also have to contend with caring for themselves.

HIV/AIDS affected households experience a marked increase in the cost of caring for the sick as well as an equally marked decrease in the income which cause financial stress. Importantly, volunteer caregivers have similar socio-economic needs as the sick people that they care for and, therefore, also need financial and material support.

In view of the poverty that is prevalent among people living with HIV/AIDS and their families, there is a tendency to focus solely on the financial and material burden of caring and neglect the physical stress and especially the psychological and emotional stress that is created by caregiving.

Chapter Six

STIGMA AND CAREGIVING

In previous chapters, I indicated that stigma has created major challenges for home-based care programmes as well as caregivers. In this chapter I explore further the issue of stigma.

Stigma has been a major problem plaguing home-based care programmes in South Africa. I found previously (Akintola, 2004) that stigma was so rife among PLWHAs and their families that HBC programmes have had problems with finding individuals willing to receive caregiving services. Even where such services were being accessed, volunteer caregivers did not know for sure the HIV status of their care recipients. Significantly, stigma is a factor that has forced care organisations to expand their services, in this instance, Sinosizo and the COC combine the care for PLWHAs with care for people with other kinds of chronic illness, in order to reduce the stigma attached to caregiving in the communities. Likewise, other home care organisations in South Africa have had to combine the home-based care for PLWHAs with care for the elderly or people with other chronic illnesses such as cancer and diabetes because of stigma (Akintola, 2004).

This was not evident in interviews and observations conducted in Uganda. Although stigma exists in Uganda, it is not so severe; people generally access home-care programmes freely. Furthermore, organisations have a free influx of patients and many of them provide care services in facilities located some distance away from communities. These centres are well known in the country as designated centres for HIV/AIDS treatment and they are accessed without fear by many patients. Most of the staff of the organisations interviewed stated that stigma is virtually non-existent. Although Hospice Uganda's care programme focuses on cancer patients in addition to HIV/AIDS patients, this is due mainly to the Hospice's focus on the control of pain and the high prevalence cancer among HIV/AIDS patients and the presence of AIDS-defining cancers (Kikule, 2002).

Many of the people interviewed in Uganda indicated that though stigma exists in the country, it is not as pronounced as it used to be years back. Some even cited the increase in the number of people registering for hospital and home care services as indication of the decrease in stigma. Many of the organisations visited are located in the city of Kampala. PLWHAs visited these organisations for care and support and there was no sign that they were hiding their statuses¹⁶. A medical doctor who had worked with a care organisation and currently serves as a volunteer doctor described the nature of stigma in the country as subtle. People don't run away from HIV positive people and rarely discriminate against them. However, it is not uncommon to find people who are newly infected feeling shame and refusing to disclose in the initial stages of the disease.

The problem of migration discussed in Chapter Five also relates to that of shame and stigma, especially among Ugandan immigrants to the city of Kampala. Informants told

¹⁶ TASO reports that 66% of PLWHAs who were counselled in 2002 revealed their status to other people around them (TASO, 2002).

me of cases where infected individuals refused to contact their families in the rural areas because they were ashamed to go back home with a disease instead of achieving a better life in the city. As one care provider explained:

‘you know when one leaves the village to come to the town, people in the village will be expecting that you have achieved something, it is difficult to send to them that you have been infected with HIV in the city’.

As a result some of these people isolate themselves from their families and prefer to die in the city instead of going back to their villages to die. I found similar fears in KwaZulu-Natal. People migrated from rural areas, which are referred to as ‘farms’, to these semi-rural communities in search of jobs in the nearby industrial area of Pinetown. The immigrants often stay in one-room shacks and when they fall ill there is usually nobody to look after them. In contrast to what obtains with migrants in Kampala however, these individuals generally can rely on families to take them back to the rural areas when they are at the terminal stages of their illness. There are a few exceptions to this however.

Interviews with care providers at Sinosizo programme also reported isolation from family as a problem for provision of care. A care provider told the story of a young man who left his mother to stay with a friend in another community because his mother remarried another man and he did not want to stay with them. Unfortunately, he did not have anybody to take care of him in his new community. His friend was not willing to care for him and he was left all alone. Reportedly, he wished to be hospitalised, but he could not afford to transport himself to the hospital.

The report of the low level of stigma in Uganda affirmed my own observations. At TASO, Entebbe for instance, PLWHAs participate in the promoting awareness of AIDS. They come in large numbers and are taken in buses to communities to carry out HIV/AIDS education using drama and songs. When asked about stigma, a senior counsellor at TASO Entebbe indicated:

‘Stigma is at the lowest level look at those people in the bus, they are all infected and they are going to villages to sing and to dramatise to create awareness’.

I also observed that as the bus was leaving another pulled up at the TASO premises from another village filled with PLWHAs. The counsellor also told me that TASO sponsors PLWHAs to travel on exchange visits to other PLWHAs in order to reduce stigma and give them a sense of acceptance.

The consensus on stigma in Uganda was not evident in interviews in South Africa. While some providers believe that the level of stigma is on the decrease, some asserted that it is not. Interviews with a counsellor working with the COC of St Mary’s Hospital revealed that stigma was so rife in the communities that people would keep members of the family who were sick in separate rooms to avoid them being seen by visitors. The counsellor recounted a particular case where a sick lady was chained by members of her family and left in her room because they did not want her to go out while they were away at work. This anecdote affirmed stories and observations of my earlier study where volunteer

caregivers also reported that family members usually locked PLWHAs up in a room preventing them from interacting with other members of the family.

However, the comparative research indicated a nuance of stigma that was common in both countries: disclosure of HIV status by parents to their children. Interviews in both countries highlighted that PLWHAs struggle to disclose their status to their children even if they do disclose to adults. In particular, mothers find it difficult to disclose their HIV status to their children. The general explanation is that the pain of disclosing to a child that one is dying is usually too difficult for many infected parents to bear.

An informant from one of the care organisations in Kampala related the story of a woman who got infected with HIV after she was divorced from her husband. She had remained unmarried after the divorce. Her two adult children who had graduated from the university were living with her and they suspected that she was HIV-positive. However, they thought that their father who had remarried was responsible for infecting their mother. They did not know that their mother had sexual relationships after divorcing their father. They were so bitter with their father while he kept pestering his ex-wife to disclose to the children that she was HIV-positive and that he was not responsible. However, the woman refused to disclose even till she died.

There was evidence to suggest that government policies may help reduce the stigma in South Africa. For example, care providers at Sinosizo have found that more people in the communities served by them are disclosing their status as a result of information given to them on the prospects of getting a disability grant. However, currently, stigma is still prevalent even among the volunteers. Shame is also preventing volunteers who are infected from accessing ARVs. Sinosizo is in the process of rolling out of an ARV programme. One of the major problems encountered is the unwillingness of their volunteers to participate in the same programme as their clients. They fear that community members might get to know their HIV status if they participate in the same programme as their clients¹⁷.

Conclusion

In this chapter, I have shown that stigma is still very rife in South Africa and it is having negative implications for PLWHAs, caregivers as well as the home-based care programmes. People living with HIV/AIDS are discriminated against and neglected by their family members because of the stigma prevalent in their communities. Caregivers, in many cases, bear alone the burden of caring for the sick because of fear of leaking the status of their patients to the neighbours. Stigma has negative effects on the work of

¹⁷ Many home care organisations operate the memory project. This is a project aimed at preparing the family of the PLWHAs for their death. The sick person is given a book and encouraged to write down memorable events in the lives of the children. Events such as history of grandparents, baptism, birthdays. The memory project also encourages PLWHAs to write wills. There is a section in the memory book where the infected person is supposed to open up to the children about the cause of illness but evidence from the comparative research has shown that this section is usually left unfilled by most parents.

many home-based care organisations in the country negatively by preventing people from accessing such programmes and many care organisations have had to expand their programmes to include other chronic diseases. This is a particular reflection of changing demands and needs that force home based care organisations to modify their original models of care.

Evidence from the comparative study shows that despite the low level of stigma in Uganda, it is equally as difficult for patients in Uganda as it is in South Africa to disclose HIV status to their children.

Chapter Seven

THE GENDERED NATURE OF CAREGIVING

In Chapter Four, I discussed the socio-demographic characteristics of caregivers of PLWHAs indicating that most of them are usually women and girls. In this chapter, I explore in further detail, the gendered nature of caregiving.

Most of the caregivers in my previous study (Akintola, 2004) were family members and members of the community who volunteer to give care. Family members included grandmothers, mothers and sisters. Only one caregiver in my sample was a child, but the study also showed that many girls were serving as secondary caregivers. Similarly, this study affirmed those findings. In Uganda, informants indicated that many of the caregivers are children giving care to their parents, siblings and relatives. When the men are infected with HIV/AIDS and die they typically leave behind children and widows many of who may be infected with HIV/AIDS¹⁸. As a result, many of the caregivers are widows and children, some of whom are also infected. There are also a lot of elderly women giving care to the infected children and grandchildren both in South Africa and Uganda. However, because of the large number of orphans in Uganda, there is a large number of infected children that are being cared for by the grandparents mainly their grandmothers.

In Uganda and South Africa, most of the caregiving activities performed by men and women are gendered. Men perform activities such as transporting to health facilities, helping to lift patients while women carry out activities such as bathing the patient, cooking, and other household chores. This is in line with the socio-cultural expectations or prescriptions prevalent in the affected communities. Men usually performed activities that relate to physical strength while women traditionally perform activities that relate to nurturing.

The problem faced by women caregivers is exacerbated by the nurturing role that they play in the household. Even when they fall sick, they still have to care for and nurture their children as well as their husbands. Such is the case of a woman in my previous study (Akintola, 2004) who was seriously ill and had to take care of her three children and her partner.

Women who are infected and caring for infected children face even greater difficulties. Many often have to deal with the emotional and psychological effect of what will happen to their children when they die. One informant at a care organisation in KwaZulu-Natal indicated that in some cases, the infected women want their infected children to die before them in order to be sure that they get proper care. They are usually afraid that if they die before their children they would not be cared for properly. However, when their children die before them, they have difficulty in coping and coming to terms with their death and go through a lot of grief.

¹⁸ At TASO, 31 per cent of 13, 807 registered clients who had tested positive to HIV/AIDS were widowed. (see TASO Annual Report for 2002)

Data from my earlier study did not include any man whose female partner had died first, leaving him to care for other sick family or household members. However, information from Sinosizo programme showed that in a few of the cases where female partners had died first, some of the male partners were willing to care for the children left behind, but struggled in practice. One care provider recounted the story of a man whose wife was sick with HIV/AIDS and had three children. The oldest child aged 18 went to live by himself, the 10 year-old child was sent to live with extended family members and only the 8-year-old stayed with the father. Nonetheless, generally, statements from interviewees in Uganda and South Africa suggested that men deliberately shirk their responsibility of caring for their relatives who fall ill. Anecdotes included men leaving their partners as soon as they discover that the latter are HIV positive; men not leaving their partners, but showing little concern especially when they are not married; men not directly being involved in caring for the sick. However, in many instances, the standard qualification was that men were often not directly involved in care because they were the breadwinners and had to sustain jobs or other income generating activities. In Uganda anecdotal evidence suggests that some men actually employ and pay for the services of people to care for their sick relative while they go out to work. Evidence of this has also been found in South Africa (Steinberg et al, 2002; Oni et al, 2002).

However, it should be noted that men shirking their responsibilities is a standard stereotype and that there is actually very little research on men in the context of home-based care for PLWHAs. Informants in Uganda, for instance, stated that it was common for the relatives, including men, of the deceased to get overwhelmed by the enormity of the problem of caring for surviving family members. This is due in part to the fact that most families and households in Uganda are affected by HIV/AIDS; hence it is common for them to have other family dependants in addition to their own nuclear family members. They are therefore overburdened with the demands of committing to a wide and widening circle of kin in need. These issues were addressed in a discussion with four widows all of whom had children with HIV and were members of a support group in the Mildmay Uganda Centre. All of them indicated that members of their husbands' families had abandoned them not because they are wicked, but because they could not cope with the problems of having to look after them and their children.

The underlying problem is the vulnerability of families and households to disintegration. In Uganda, married women usually find it difficult to bring their siblings or relatives into their own homes when their parents die because many men refuse to accept them. As a result, a number of women in Uganda have had to leave their matrimonial homes and become separated from their partners in order to care for their relatives. It is also common for women who are unable to care for their siblings to marry them off to men with the agreement that they take proper care of them.

A representative of Sinosizo related the story of a woman who was sick and had three children and was living with their stepfather. When she was about to die she requested that her sister care for her children. But when she died, her will did not include her sister's name so she did not get any part of her property. She was so angry that she

declined to take care of her sister's children. The stepfather also did not want the eldest child and the boy joined up with gangs and is now currently wanted by the police for crimes, in this case Sinosizo had been fortunate to secure sponsorship for schooling for the boy and so alleviate the problems facing the family.

Gender, plays a major role in increasing the burden of female caregivers. This was highlighted by research in Uganda in reports of 'property grabbing'. This is the practice of forcefully taking away property from the widow of men that die. In other words, for many women, caring for a sick husband is economically stressful and then compounded upon his death if his kin use opportunity for their own benefit. Although property grabbing is a practice that serves to undermine women's ability to cope and care for themselves and their children after the death of their husbands, the role that women play in perpetuating this practice was highlighted in a number of interviews. There was anecdotal evidence that women were responsible for the enforcement of the practice of grabbing of properties of dead people. The four women mentioned earlier were unanimous in stating that 'the women in the husbands families are the worst offenders' who insist that property be snatched from the surviving wives of their brothers and sons. One woman who had lost a brother described how her paternal kin had decided to take away her brother's property from her wife and children. She said she had discouraged them but her sister insisted. She was so disgusted and had to ask her sister to consider if she would want the same thing to happen to her if she lost her own husband. According to her, 'it was when I said that, that she changed her mind saying she would not want to have that experience herself'.

Conclusion

Most of the family caregivers as well as volunteer caregivers are women and have to contend with the burden that falls to them as a result of their gender. There is also gendering in the volume of work that women do and in the nature of their work as well as the consequences of caregiving. There is clearly enormous stress for mothers who are infected because they have to care for themselves, their children and also worry about what will happen to their children when they are dead. This is partly because men and, indeed society, provide very little support for the caregivers. It is also disturbing to note that in some cases, women are at the forefront of gender discrimination. Anecdotal evidence has shown that women have participated in dispossessing widows of their family property.

The tragedies and failures of family, kin, community and society in dealing with HIV/AIDS highlight common vulnerabilities. There is a threat of disintegration of families, children are dislocated and traumatised by the stress and sometimes collapse of their families.

As discussed earlier, home-based care organisations have been drawn into meeting this challenge. In Uganda, organisations have achieved some success, but in South Africa home-based care organisations have been less successful in meeting this challenge.

Chapter Eight

LESSONS LEARNT AND CHALLENGES FACED BY CARE PROGRAMMES

Networking and Partnership

One of the main findings is the higher level of networking and partnership that exists among care organisations and the government in Uganda, compared to South Africa. Networks and partnerships exist in the establishment of care organisations and in the daily work.

In Uganda for instance, the government of Uganda has worked closely with Hospice Uganda and Mildmay in the establishment of these organisations. In the case of Mildmay, the government provided the land for the project and signed a 10-year contract with Mildmay to manage the centre after which the Ugandan government is expected to take over the centre. Most of the NGOs that carry out home-based care refer their patients to other NGOs such as Mildmay Uganda that has specialized services for PLWHAs and Hospice Uganda, which specializes in palliative care. In addition, 80% of patients that come to Hospice Uganda, are referred from the Mulago Hospital, the teaching hospital of Makerere University. Although Mulago hospital has a palliative care unit, the hospital cannot cope with the large number of PLWHAs. Twenty percent of referrals are also received from volunteers in the communities, and private health facilities and others come by themselves without being referred. There is also a partnership between the home care unit of St Francis Hospital Nsambya and Meeting Point, Kampala. Since Meeting Point does not have Doctors on their staff, the medical team from Nsambya carry out home visits to patients served by the Meeting Point. They also refer serious cases to St Francis Hospital, Nsambya. The Mildmay Centre receives referrals from government and private hospitals with which they have functional networks. TASO has one of its biggest offices in the premises of the government teaching hospital, the Mulago Hospital. In addition, the TASO's seven centres, which are located in seven different districts in Uganda are affiliated to district hospitals.

In South Africa, care organisations do network with each other, but in comparison to the evidence from Uganda, less intensively and less effectively¹⁹. For example, COC has networks with other NGOs such as the Dream centre to which it refers some terminally ill patients. Sinosizo assists the COC in training their volunteers. Sinosizo has, however, had problems with referrals of patients either to the local clinics or to district hospitals. There are no formal agreements with the hospitals and staff use their personal networks by referring only to particular doctors with whom they had previously established relationships. Furthermore, there is little collaboration with the national and provincial governments. The COC, for instance, has not received any kind of funding assistance from government since its inception. Sinosizo has received funding assistance through personal networks with people at the department of health.

¹⁹ Research by Jurgensen (2003) in one KwaZulu-Natal district showed that NGOs offering care for orphans and vulnerable children had very limited networks and that most operated in isolation.

Although care organisations in South Africa assist their patients in preparing their papers for social grants and some have actually recorded successes in preparing papers, securing the grants have been difficult. Evidence abounds from my previous study on patients who had been referred to the social welfare department, but were not able to secure their grants before they died. The low success rate with the securing of grants appears to be due to the lack of effective networking between the department and home-based care organisations.

Staffing and coping with attrition

Home-based care organisations in South Africa lack staff capacity due to lack of funds. Although many organisations in Uganda expressed the need for more funding to meet their growing commitments, lack of staff was not cited as a common problem. Three organisations namely, Hospice Uganda, Mildmay Uganda and TASO seemed to be well staffed. The other organisations have international financial support as well as government support. The level of funding and higher level of staffing is reflected in the use of professional teams that visit homes by several organisations and the extent of networking to cover shortfalls in capacity. In sum, care organisations in Uganda appear to be better staffed and harness available resources via networking more effectively than similar organisations in South Africa.

In South Africa there is a greater reliance on volunteers. This is due mainly to the fact that NGOs have problems convincing donor agencies to fund salaries of staff. A care provider at Sinosizo recounted how her organisation almost lost the opportunity to receive funding for their projects when they included a stipend in their proposal. The donor told them to remove the cost component or lose the funding. Eventually they had to remove the budget for stipends.

The lack of adequate funding has implications for home care programmes. As the previous chapters have highlighted, home care programmes in South Africa function less well than in Uganda. Indeed, comparing the models in use in Uganda to South Africa, it is clear that the former have refined home-based care to the point where services offered exceeds the capacity of individual organisations and there is less reliance on volunteers.

Evidence from home-based care organisations that make use of volunteers show that they usually experience high rates of attrition. For example, informants at Sinosizo home-based care reported encountering problems in recruiting volunteers for their programmes. They also experienced very high rates of attrition from their volunteers. For example, between January and March 2004, the organisation lost four volunteers out of a total of about 200.

One problem that aggravates the attrition rate, according to the head of the home-based care department of Sinosizo, is the fact that Community Health Workers (CHWs) receive payment for their activities. Their duties are not as cumbersome as that of the volunteers because they do not carry out hands-on care for PLWHAs. CHWs carry out health education and also refer patients who have HIV/AIDS to volunteers. Recently, Sinosizo home care programme almost lost all its volunteers when an announcement made by

South Africa's Minister of Health was misconstrued to mean that volunteers would be paid 1,000 rands per month. It was later found that the minister was referring to the CHWs.

Managing Conflicts and Misunderstanding

Previous discussion has highlighted the demands on care organisations to extend their services to meet the changing and wide range needs of HIV positive patients and their families. One point not covered so far is the demand for mediation of organisations in family conflict that stem from the trauma of death in families. The research in Uganda highlighted this issue. For instance, in Uganda, AIDS Widows and Family Support of Nsambya Hospital had constructed houses to improve its care of orphans, but there were occasional conflicts in operating these homes. For example, some male heads of child-headed households believe that they should be given the same privileges as their fathers, insisting that they be given separate bedrooms while their other siblings shared bedrooms. Directly related to this is the problem that arises when PLWHAs die and have houses.

Conflict is not restricted to those among affected families but sometimes occurs between the care providers and the affected families. For instance, one source of conflict arose in Uganda, in 2002 when the World Food Programme started to distribute food to HIV affected households. One of the requirements for people to be qualified is that affected households fill in a questionnaire to establish their eligibility by eliciting information about different aspects of the families' lives. Information asked for included details of property owned by the family. However, many families fearful of losing their property, are usually reluctant to divulge that information; reportedly they even chased away volunteer workers. An official of one of the organisations described an extreme case of a mother who was caring for her daughter who had lost her husband to AIDS. The daughter had a plot of land, which was the family property. When volunteers asked questions about her properties, she mentioned that she had a plot of land. Further questions on the land provoked anger on the part of the mother who went into the room to bring a machete and threatened to kill the volunteer. Care organisations have mechanisms for the resolution of conflicts. Elderly women who serve as volunteers in the communities are often used to solve conflicts because they are more respected than the providers themselves.

Care providers at COC indicated that they sometimes encounter situations when family members seek to dispossess orphans of their inheritance. The grants given by government also presents a problem as some family members fight to gain custody of orphans in order to have access to their grants.

Stigma and discrimination

Stigma and discrimination affects care organisations in two major ways. One is the fact that people are reluctant to access the services of these organisations, which has led many of the organisations in South Africa to include the care of other chronic illnesses in their

programme. The second is that some families abandon their relatives in care centres. At the Dream Centre, for example, care providers complained that patients come into the facility without any form of identification while some give false names in order that care providers may not be able to trace their families. Moreover, care organisations in Uganda reported a problem arising from families who abandon their sick family members in the hospital due to the fact that they do not want to be seen as associating with them. This has put a lot of strains on the Centre because they have to organize for the burials of such people without knowing where the relatives are.

Dealing with poverty

In an attempt to deal with poverty, care organisations often encourage volunteers to assist start support groups and start income generating projects. However, such projects compete with the primary duty of the volunteers, which is home-based care.

One of the problems reported by volunteers in my previous study (2004) was that of over expectation by members of HIV affected families. They expect the volunteers to bring them food that they themselves cannot even afford. This problem was also reported by other care organisations that participated in the assessment. For example, the Sinosizo started distributing food parcels via volunteer caregivers to affected households especially to patients who were on TB drugs. However, staff noticed that families did not welcome the volunteers when they did not arrive with food parcels. Sinosizo therefore decided not to allow volunteers take food parcels to the households anymore. Distribution of food parcels is now the work of the social worker. However, often there are not enough food parcels to give to all the patients that need them. Furthermore, the quantity of food is usually insufficient to sustain the sick person.

Funding of Care Organisations

Funding is probably the single most pressing problem facing organisations giving care to PLWHAs and orphans. Care organisations are completely dependent on funding from donors and this presents it's own problems. Funding is secured by writing proposals to funding bodies. Funding support is also received from individuals abroad. For instance, at the AIDS Widows and Orphans Family Support, Nsambya, Uganda, in addition to the funding support received for the programme from donors, the organisation also seeks sponsorship from individual sponsors for the education of orphans.

Some of the organisations operate cost recovery programmes. Although fees charged are subsidized and most of the money recovered is not enough to cover the expenses and running cost of the programmes, it reduces the cost to the organisation. At Mildmay Uganda, patients are classified into three categories. First are the children who are treated free of charge. The Centre created a hardship fund for the treatment of children up to age 18. Adults who cannot afford to pay also benefit from the hardship fund. The second category is adults who are referred to as ordinary patients. Ordinary patients are those who cannot afford to pay for ARVs and are treated for opportunistic infections. These patients pay between \$1-3 dollars per visit. The third category consists of patients who

are able to pay for their own treatment and ARVs. They are referred to as private patients and they pay between 5-15 dollars per visit.

What is clear from this is that in South Africa, care organisations are still struggling to fund home based care which provides mainly basic nursing care with very little medication while organisations in Uganda are able to provide comprehensive medical care and to subsidize the costs for patients.

Chapter Nine

CONCLUSIONS

Care organisations in Uganda developed long before those in South Africa. The common thread in the development of these organisations is the overstretching of hospital facilities which has led to development of home-based care programmes. In Uganda and South Africa, most of the organisations assessed in this study were initiated by hospitals, individuals and Christian groups. However, the origins of the organisations that have developed to tackle these problems vary.

Home-based care organisations tend to be located in areas of highest prevalence of HIV/AIDS. In Uganda, they are mostly located in Kampala while in South Africa they are located more in semi-rural and rural areas. The organisations operate different care models for people with HIV/AIDS and AIDS orphans. Most of the organisations in South Africa operate community home-based care programmes that make use of volunteers who visit homes of the sick people to care for them. One organisation in South Africa operates an innovative and unique step down care model filling the gap between community home-based care and hospital care. Semi-comprehensive home-based care programmes are operated by most of the big hospitals in Uganda where a medical team visits the homes of the sick people. TASO Uganda is the only organisation that operates a comprehensive programme that offers a combination of services that includes prevention treatment and care of PLWHAs. One organisation, Hospice Uganda offers palliative care for PLWHAs while another Mildmay Uganda offers tertiary care.

This study highlighted the burden of caring for PLWHAs. The burden created by caregiving falls disproportionately on women and leads to negative consequences. Most of the family caregivers as well as volunteer caregivers are women and have to contend with the burden that falls to them. Women also have a disproportionate share of the caregiving activities as well as have to deal with substantive negative physical, emotional and psychological as well as social and economic consequences that arise as a result of caregiving. The fact that volunteer caregivers have similar emotional and psychological as well as socio-economic needs as the sick people calls to question the rationale for using them without adequate support. The fact that caregivers rarely report physical, emotional and psychological stress because of social-cultural factors is very disturbing and this underscores the need for studies to understand better the nature of the stresses on caregivers. There is a tendency to focus solely on the financial and material burden of caring and, in the process, to neglect the physical stress and especially the psychological and emotional stress that of caregiving.

There is also a threat of disintegration of families, children are dislocated and traumatised by the stress and sometimes collapse of their families. The pain of mothers as expressed in the fear of disclosing their HIV statuses to their children, the fear of losing their children and of dying before their children highlights the psycho-social burden of caring for PLWHAs. The prohibitive costs of caring for someone living with HIV/AIDS and the

relative poverty of many of those who are typically infected puts untold economic pressure on the carers.

The study identified various models of care that fill different areas of need of people living with HIV/AIDS and their families and no single model is adequate in itself to meet the complex and varied needs and demands of the PLWHAs and the affected families. The experiences of different care organisations shows that that they have had to constantly adapt to the changing demands of care.

In Uganda, the care of patients have been refined in many instances to the point that medical professionals and paramedic team provide support for volunteers whose main duties are to recruit patients and provide frontline care services in homes. Patients are thus provided with specialised medical care as well as support services by this team. Thus a continuum of care services, which includes basic nursing care, medical care as well as bereavement support, is provided to patients and, in many instances, care organisations achieve this by creating networks and partnership with other care organisations. In this way, resources are pooled enabling these organisations to offer different services to patients.

This is in contrast to the common models in South Africa, which use volunteers to provide basic nursing care as well as moral and spiritual care. In practice, these models are deficient because they cannot offer patients the necessary care beyond basic nursing care. The assumption is that the patients will die anyway and that what they need is the provision of end-of-life care. The treatment of opportunistic infection is rarely achieved because bedridden patients rarely have access to medical personnel. Although, many of the care organisations lay claim to palliative care, there are concerns about the effectiveness of such programmes since care is usually limited to basic nursing care. In South Africa, the burden of responding to the changing demands of patients and families is carried by the caregivers.

In essence, care organisations in Uganda operate community-oriented care in contrast to the community-based care commonly operated in South Africa. The use of community-oriented care has greatly improved services to the sick people and reduced the burden on the caregivers. There has also been remarkable success in terms of reversing the state of the ill thereby improving their quality of life and prolonging the life of PLWHAs. The practise of care organisations in South Africa shows that the country is way behind Uganda. Care organisations are merely responding to needs as they arise in an approach that looks very much like crisis management and there is no overall coherent approach or framework in practice.

In Uganda, successes recorded in the models of care operated has led to rising demand, reflected in increasing numbers of sick people accessing services rendered. This has created new challenges of how to meet the increasing number of people who need services. Challenges still exist in securing funding for the expansion of projects and in mobilising more support for affected families as the demands of such families increase.

Although care organisations have achieved remarkable successes in the provision of care to the PLWHAs and support for affected families, a lot still needs to be done to ease the burden on the caregivers and the affected families. The stress of giving care to an infected person, particularly those who are bedridden is having a negative impact on the caregivers. Evidence from Uganda shows that care organisations have been able to adjust initial models to the emerging needs of the people and evolve over time. In contrast, the study has highlighted the need for critical review of home-based care programmes in South Africa. The effectiveness and sustainability of home-care in this country is questionable. This study suggests that many families are not in a position to offer home-based care without undermining the wellbeing of family members. The needs of affected households are enormous, increase and become more complex over time. This highlights the need for substantial investment in the care of people living with HIV/AIDS and their families

POLICY RECOMMENDATIONS: KEY ISSUES FOR SOUTH AFRICA

- 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 as is being practiced in many communities may contribute to the non-achievement of this goal. The use of girls, and in some cases boys, as primary or secondary caregivers affects their education and this is likely to undermine the attainment of the Millennium goals. There is therefore the need to protect girls from actively giving care in homes. This can be achieved if the state of households and the capacity of such families to care for the sick are considered before hospitals discharge patients.
- There is a need to review primary health care models in the face of HIV/AIDS. Community Health Workers need to take more active role in the care of the sick people such that their work is synchronised with that of the volunteer caregivers. There is also the need to make caregiving a career for volunteers in order to make it attractive and reduce attrition. This will definitely bring more immediate and direct costs to the government but will in the long run be a wise investment.
- There is a need to recognise that the demands of affected families is varied and complex and not restricted to basic nursing care. Therefore, home-based care programmes need to move from current care models which provides basic nursing care to community-oriented care which provides holistic care for PLWHAs as well as supportive services for the sick person's family and the care of orphans. In this proposed model, hospitals and medical personnel should be more involved in home care. The experience of Ugandan organisations shows that high level of networking and referrals can help reduce shortfalls in capacity and finances for the proposed model. Volunteers can then be used to enhance care for PLWHAs and not be the main providers of care.
- In view of the psychological and emotional impact of caregiving on the caregivers, there is need for the introduction or revival of mental health programme at the primary care level. Importantly, caregivers including children need mental health care and support to cater for their emotional and psychological

problems encountered while caring for the sick. They should therefore be constantly evaluated to determine their support needs.

- There is a need to recognise that home-based care is not a cheap alternative to hospital care, rather the costs are borne by on the caregivers and this usually go unnoticed. The overburdening of caregivers could be addressed by providing support and material assistance to volunteers as well as family caregivers.
- There is need for further research into the support needs of caregivers of PLWHAs and the cost of providing such support.
- At root, in South Africa, home-based care programmes need to be re-formulated and conceived in terms of being 'community-oriented' rather than 'community-based'.

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