

Chapter 34

Models of Community-Based Care

Overview

This chapter describes the various models of community-based care that are being used in sub-Saharan Africa (SSA) to expand the geographic area of health care coverage. These different approaches to care are being implemented in communities restricted by scarce resources and a dearth of health care workers (HCWs). Palliative care teams are often restricted to a few doctors and nurses, sometimes with no rehabilitation or social work team members. With careful assessment and planning, communities can develop programmes appropriate to their circumstances to extend care to a wider circle of families infected and affected by HIV/AIDS.

Within the wide range of models for community-based programmes and methods for delivering care, certain components are essential to providing palliative care. The most critical of these are pain and symptom control and holistic care that addresses the financial, social, emotional, and spiritual needs of the family. Whether or not a programme calls itself a palliative care (or hospice) programme, these elements enable community-based organisations to help relieve the suffering of people living with HIV/AIDS and their families who would otherwise not access services.

Authors

Kath Defilippi

David Cameron

Anne Merriman

At a Glance

Why Community-Based Models are Important

Getting Started

The Continuum of Care

Methods to Deliver Community-Based Palliative Care

Components of Community-Based Home Care

References

Models of Community-Based Care

Table of Contents

Overview	451
Why Community-Based Models are Important	453
Getting Started.....	454
The Continuum of Care.....	455
Methods to Deliver Community-Based Palliative Care	457
Components of Community-Based Home Care	461
References	464

Why Community-Based Models are Important

The diversity and sheer volume of care required to care for people affected and infected by HIV/AIDS in SSA necessitates challenging conventional approaches to health care systems to increase coverage. There is an unprecedented need for increased access to quality care that provides much more than mere hand-holding and kind words, especially in this pandemic, characterized by life threatening infections and malignancies.

Informal home-based care by family members who look after their sick and dying at home without training or external support is simply not adequate for people who are seriously ill with HIV/AIDS (Uys, 2003). Community involvement is a pivotal component of successful and sustainable programs.

The notion of balancing quality and coverage is in keeping with the findings of a recent survey of models, services, challenges, and priorities related to HIV/AIDS end-of-life care in SSA. Of the home care programs interviewed, 94% reported challenges in pain control and required capacity building with regard to monitoring and evaluation (Harding, 2003).

The current supply of programs already falls far short of the demand caused by this epidemic, which is yet to peak. Most frequently, people with the greatest need have least access to any form of organized care. HIV/AIDS is rampant in communities where gender inequality is culturally entrenched. The disease continues to disproportionately affect marginalized and impoverished groups, especially powerless women and their children.

Hospital and clinic services are stretched to capacity and in danger of becoming overwhelmed. The stress caused by the vast and increasing number of people living with HIV who require care is exacerbated by a shrinking supply of HCWs. In addition to staff dying of HIV/AIDS, skilled health care professionals are taking jobs with externally-funded, better-paying HIV/AIDS programmes and emigrating to developed countries for better-paying jobs. Many African health care institutions currently have a critical level of vacant posts that they are unable to fill.

It has become imperative for community-based home care programs to supplement hospital and clinic services. Ensuring that community-based programs incorporate an effective clinical component that includes palliative care is of primary concern. In this situation, community caregivers should be issued with suitably equipped home care kits and be taught clinical skills that have traditionally been reserved for professionals, who have become a scarce resource. The professionals in turn need to be empowered with supervisory, delegation, and management skills.

Involvement and support of local communities in both planning and implementation of the home care program is essential in terms of its acceptability and long-term sustainability (Defilippi, 2003).

Getting Started

In planning to start community-based palliative care services, the three foundation measures of the World Health Organisation must be kept in mind: training, drug availability, and government support and will (see Chapter 35: Role of Government). It is best to conduct a feasibility study to develop appropriate policies and plan the best array of services before developing programmes.

However, the programme will often have to start without the three foundation measures in place. If so, the patient and family will always be firmly in place as the centre of the world for the palliative care team, and this is where the programme can begin. A suitable model can be adopted and adapted as the team learns the needs and conforms to the economic, cultural, and social aspects of care in their area.

Palliative care services will commence in many forms in the various countries of SSA (see Box 34.1: Examples of Different Starting Models). However the major ingredient for the service is a knowledgeable person (Champion calibre) with fire in the belly who is willing to respond to the needs of those dying in the community as well as the needs of their families and caregivers.

Box 34.1:

Examples of Different Starting Models

- Palliative care may commence as an integral part of an already established health facility. Muheza Hospice Care in Tanzania was grafted onto Teule Hospital, an already successful mission hospital in Muheza. The Hospice now has an extensive outreach and day support programme.
- Palliative care can also begin as established palliative care services provided by NGOs and then be grafted onto government health services at each level. Examples include South Coast Hospice in rural KwaZulu-Natal, other South African hospice programmes, and Island Hospice in Zimbabwe.
- Palliative care is also being grafted onto already established support services such as Kitovu Home Care and The AIDS Service Organisation (TASO) in Uganda.
- Palliative care can also start from scratch. Hospice Africa Uganda commenced with enough funding for three months salary for three persons and an ancient Land Rover from a donor. Home care was the vision, but patients began to come to the front door of the initiator's home looking for assistance from the early days. The service would not have commenced unless the Ministry of Health made oral morphine available. The Minister himself authorised importation of powdered morphine, which can be reconstituted. The wonderful changes in quality of patients' lives brought many seeking similar relief for their loved ones. As more people saw the peace of patients no longer suffering intractable pain, more were referred and more HCWs sought training. The government was completely on board after five years of witness through the service.

The Continuum of Care

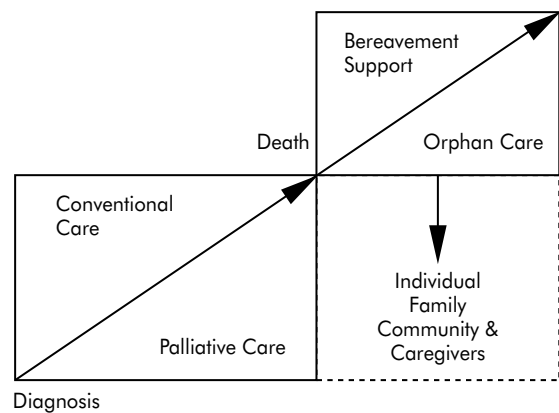
The Range of Services

Health care systems exist to address the prevailing needs of individuals, families, and communities, and as such should form part of a dual continuum of care. On the one hand it is important for individual patients and families to have access to a continuity of care that addresses the entire disease spectrum. This includes care from pre-diagnosis through the asymptomatic and symptomatic phases of HIV infection, the prevention and treatment of opportunistic infections (OIs) and HIV, pain and symptom control, care at the end of life, and bereavement care (see Figure 34.1: Continuum of Care Through the Disease Process).

On the other hand, a continuum of services that allows for easy access across a variety of settings is vital for the well-being and optimal management of people living with HIV/AIDS (see Figure 34.2: HIV/AIDS Continuum of Care Across Community Settings).

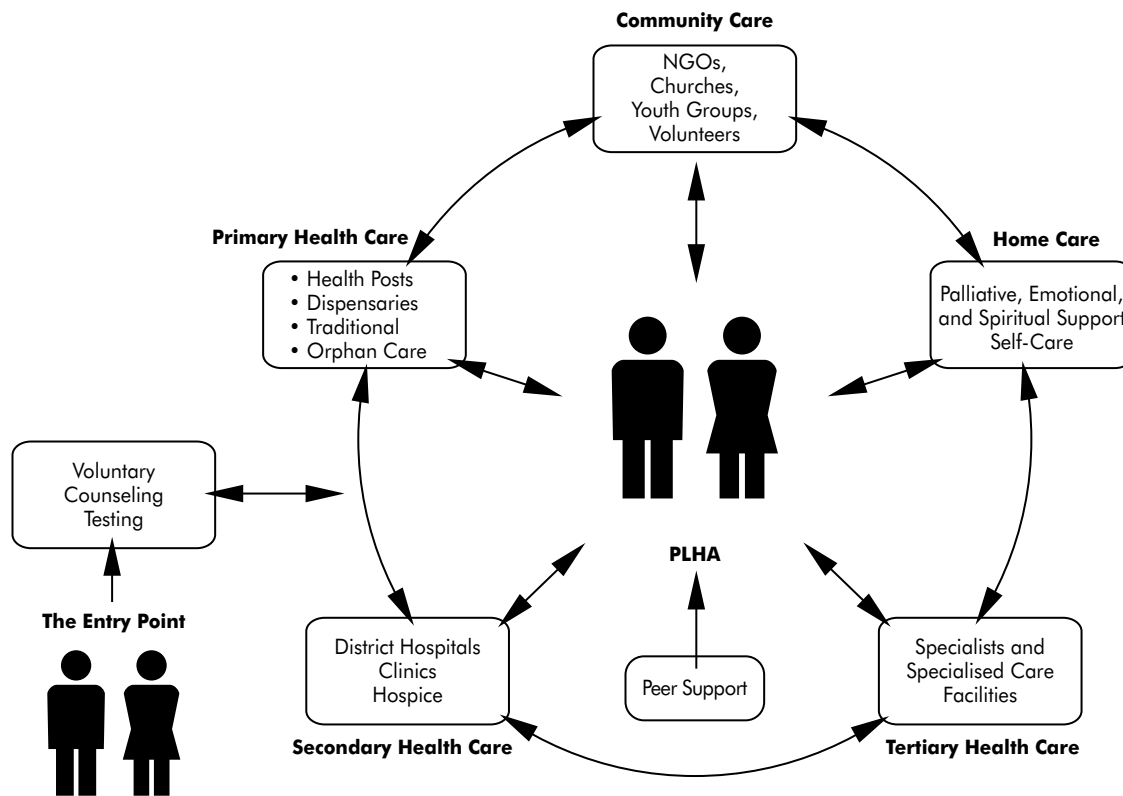
In addition to benefiting individual patients and families, this dual continuum offers considerable advantage for the entire community in terms of equitable access to quality care coupled with an uncomplicated and effective referral system. It also impacts positively on an array of HCWs—from grassroots level of community caregivers and lay counselors to teams of multidisciplinary professionals and managers.

Figure 34.1: Continuum of Care Through the Disease Process



Source: Defilippi, 2002.

Figure 34.2: HIV/AIDS Continuum of Care Across Community Settings



Source: WHO/UNAIDS, 2000.

Inpatient Hospital Care

As in other parts of the world, people in SSA traditionally seek hospital care for serious health conditions. The nature of the epidemic has made it impractical and economically impossible for the majority of HIV/AIDS care to be provided in an inpatient setting.

The role of hospital care, however, remains crucial to individual, family, and community health. Budget constraints challenge hospitals to be less rigid and to use their resources optimally. Business cannot just carry on as usual and be expected to remain effective in a critically changed environment. This invariably requires a change of routine within the institution and an evaluation of existing criteria and systems. At the very least, criteria for admission and discharge need to be revised.

Discharge Planning and Referral to Community-Based Services

Careful discharge planning with integration of patients and families into any existing network of community care should be required in policy and practice. In the case of home-based care, a written referral form should include:

- Consent from patient and family
- Documented diagnostic evaluation
- Treatment regimen
- Confidentiality of HIV status

Patients and families should also be given:

- Accurate information (ideally a brochure) regarding the likely intensity of care and social support provided by the home care program (to avoid unrealistic expectations and disappointment)
- Where possible, an initial supply and assurance of continued access to medication
- Where possible, supplies such as soap, dressings, and gloves

Outpatient Services

Ideally people with HIV and their families should have ongoing access to medical care whilst at home, at an outpatient clinic. This may be situated either within the hospital or at a location closer to where they live, such as a primary health care clinic.

Methods to Deliver Community-Based Palliative Care

Box 34.2:

Methods to Deliver Palliative Care at the Community Level

- Home care teams
- Outreach team
- Roadside clinics
- District PC teams
- Hospital-based palliative care teams
- Palliative care teams grafted onto support organisations
- Day care (community initiative)
- Community-based carers link
- Inpatient hospice
- Small homes for care (using relatives to care)
- Caring teams from faith-based organisations (FBOs)

Home Care Teams

Many palliative care programmes will use teams to provide care in the home. Many poorer countries have to commence in such a manner. However, against so many odds, the service can fail if there is not a visionary person to guide the team through these difficulties.

Uganda: Little Hospice Hoima commenced in 1998 starting in a shop front in an economically restricted district of the city. They had no electricity or running water. They made home visits on foot or using a *borda borda* (motor cycle or bicycle which carries one passenger on the back). They also saw patients who came to the shop with the 'Welcome to Little Hospice Hoima' sign outside. This has now grown and they have their own car to do home visits, have day care monthly, and visit the local District Hospital as their palliative care team. The team works together with community vigilantes who they train to identify those in need of services, many of whom have never seen a health professional but are now dying in pain from cancer or HIV/AIDS. They also do outreach programmes and roadside consultations and train health professionals.

Outreach Teams

Outreach teams expand the geographic area a programme can cover. The palliative care team travels to a centre beyond their catchment area limit and spends the day seeing walk-in patients. They also may go to the homes of those too ill to reach the centre.

South Africa: South Africa has a mobile primary health care service with well-equipped mobile vans that visit set clinic points in remote areas to service clients who reside too far away to benefit from the fixed clinics. The South Coast Hospice has for many years encouraged and sponsored professional primary health care nurses from both fixed and mobile clinics in the southernmost health district of KwaZulu-Natal to obtain a qualification in palliative nursing care. This policy has contributed significantly to ensuring that clients have access to palliative care across the continuum, as shown in Figure 34.2. Another beneficial intervention has been the introduction of 'drop in' community centres, often linked to the provision of voluntary counselling and testing as well as the provision of ongoing support and helpful information.

Roadside Clinics

Roadside clinics happen when team members arrange to meet a patient or their relative at the side of the road to consult and give treatment. Roadside clinics can allow the team to see more patients in a day or to see patients outside the programme's catchment area. This method often leads to the development of a more formalised outreach clinic (see Outreach Teams, above).

District Palliative Care Teams

Health care districts establish palliative care teams, which may be attached to a non-governmental organization (NGO) or to a Government District service. The teams are headed by a palliative care coordinator and set up services and training for the district. They may also spearhead drug availability with the District officials.

Hospital-Based Palliative Care Teams

These are teams which see referrals in the hospital, commence on treatment, and then communicate with teams or caregivers in the community to provide a continuum of care. They assess the patient whilst they are in hospital and advise on the continuum of suitable palliative care after discharge to the community.

A number of hospitals have embarked on providing a home care service themselves. However, hospices, FBOs, and NGOs currently provide the bulk of home-based care.

South Africa: A recent highly successful innovation in Southern KwaZulu-Natal has been the introduction of hospital-based palliative care teams specifically for the purpose of linking hospitalized patients to home care services. Typically these teams consist of a nurse trained in palliative care and a lay counsellor, as well as a doctor and social worker, who incorporate a daily palliative care ward round into a myriad of other commitments. The nurse is the link between the hospital-based palliative care team and the home care program, maintaining daily contact with the other members of the palliative care team and ongoing liaison with the home care team. The team gives individualized holistic care to the patient and provides the family with information regarding basic nursing care, infection control, nutrition, and medication. Introductions are made to relevant community services such as home-based or day care programs.

Grafting Palliative Care Onto Existing Community-Based Support Organisations

Many support organisations have networks into the communities and involve caregivers at the village level. Using these community-based organisations (CBOs) is obviously a way to rapidly scale up care of the critically ill and those at end of life within the community. However in taking on palliative care services, the CBOs must adapt their frequency of home visits. Palliative care must be available for any crisis. CBOs should have a separate palliative care team to take referrals from the larger support team and provide more intensive care. These teams should have at least one palliative care nurse or clinical officer to take responsibility, train and guide the team. The Kitovu Home Care Programme in Masaka, Uganda has its own palliative care team.

Community Day Care

Day care is often part of the continuum of services in developed countries, but there is a role for community day care even in low-resource countries. Here, the community comes together and prepares a day for the patients receiving palliative care to meet together in a centre, which may be the community centre or a local church. Volunteers care for the patients, transport them to the centre, cater a meal and snacks, and offer diversional therapy and counselling. This gives the family carers some time off and enables the sharing community to attend to spiritual, cultural, and social needs in groups. Day care may not be a stand-alone service, but it can be part of a comprehensive set of services.

Community-Based Caregivers Link

Community caregivers or vigilantes are carefully selected and trained volunteers who identify and care for people within the community who are in need. They work closely with the formal palliative care team. Individuals doing this form of community work find even those who have not accessed health care in the past who now are dying of cancer or HIV/AIDS.

Inpatient Hospice

Inpatient hospices are expensive to run and not so much in demand in developing countries, where families are usually prepared to provide care. However, families are more prepared when community supports such as those described above are in place, in case families have problems. All being equal, people with HIV/AIDS and their families prefer for care to be provided at home (Kikule, 2003; Sepulveda, 2003).

Inpatient units are ideally placed to provide intensive clinical teaching. They often develop protocols for treatment and care that are then rolled out to benefit the broader community. Both Jaja's Home, which is part of Mildmay International in Kampala, Uganda and St Nicholas Hospice's Sunflower House in Bloemfontein, South Africa, provide specialised inpatient paediatric palliative care.

Small Homes for Care

Some support organisations, under pressure, have provided small homes where relatives can care for patients or homes where patients rejected by their families can reside. An example is the Kamogyia Christian Community in Kampala, Uganda.

Care By Faith-Based Organisations

Many FBOs have developed caring groups ready to move in and assist with patients in the end of life. These groups work well when networking with other palliative care services in the area. However it is important to carefully assess such well-doers, because there are some who ask patients to leave the religion where they have had peace, offering them cure if they become members of another faith. This does not benefit patients who have come to peace in their own spirituality. Bringing in a new religion at this stage only breaks their peace of mind.

FBOs can provide many support services in the community, such as accommodation for day care or outreach clinics. Moreover, the spiritual support they provide is very much appreciated by patients and families, and they can be involved in prayer groups in the communities.

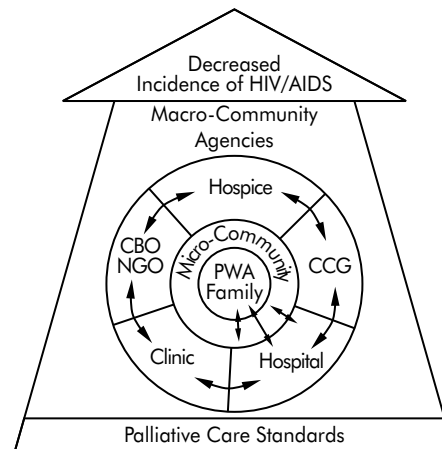
Joy Hospice: One Christian church in Mbale, Uganda has commenced a hospice where the initiator was inspired to take patients into her own home. From this beginning they now have an inpatient hospice run by the church with the leadership of the founder. (personal communication, Jane White). This is adapted to the economy of the local community and the caregivers are relatives with some supervision from the palliative care team.

Integrated Community-Based Home Care

Finally, the collaborative model of integrated community-based home care involves not a single organization, but the collective efforts of many organizations working together. An NGO, such as a hospice, works closely with government hospitals and primary health care clinics. Existing community and faith-based initiatives are drawn in and strengthened by means of active networking and the enhancement that flows from non-competitive mutual support. This system allows for trust to be built between all the stakeholders and results in an effective referral system.

The needs of the person with HIV/AIDS and his or her family are central, with the goal of providing them access to the dual continuum of care as described above. This spans the time from pre-diagnosis onwards, crossing a variety of care settings that may range from home to hospital and incorporate a collaborative network of community care (see Figure 34.3).

Figure 34.3: Integrated Community-Based Home Care Model



Key: CCG = Community caregiver
 CBO = Community-based organisation
 NGO = Non-governmental organisation
 PWA = Person with HIV/AIDS

Source: Uys, 2001. Reprinted with permission.

South Africa: The Integrated Community-based Home Care (ICHC) model was developed in 1996 by South Coast Hospice in response to the HIV/AIDS epidemic in rural KwaZulu-Natal. It has been adopted by the Hospice Palliative Care Association of South Africa (HPCA) and written up as a best practice by the HIV/AIDS/TB/STI Directorate of the South African National Department of Health.

ICHC was subsequently piloted by HPCA in conjunction with the University of Natal and found to be replicable and flexibly effective in metropolitan, urban, peri-urban, and rural settings across South Africa. The South African National Department of Health simultaneously provided separate tender funding to HPCA for the development of a curriculum for community caregivers who are inherent to ICHC. Funding was also provided for the development of palliative care guidelines in terms of the

compilation of an Audit Tool to measure patient and family satisfaction with ICHC. More than 40 South African hospices provide ICHC. The specifics of the model are adapted in line with the needs and resources of particular geographic areas but in every instance it is characterized by extensive networking and a strong public/private partnership.

Muheza Hospice Care (MHC) is a palliative care programme centred in a Mission hospital which is a district designated hospital (DDH) in rural Tanzania involving elements of all the models of palliative care integrated together (Personal communication from Dr. Karilyn Collins and presentation at APCA Conference, Arusha, June 2004).

Components of Community-Based Home Care

Programme Components

To provide effective palliative care, a community-based home care programme should include the following components:

- Proper pain and symptom control (see Chapter 4: Pain Management)
- Effective management of OIs, including prophylaxis and treatment (see Part II: Clinical Supportive Care)
- Culturally-sensitive holistic care that addresses the devastating nutritional, educational, financial, social, emotional, and spiritual needs of people with HIV/AIDS and their families (see Part III: Psychosocial/Spiritual and Traditional Care and Part IV: Environmental Factors that Influence Care)
- Early identification and optimal support for, or placement of, orphans (see Chapter 31: Family and Community Support)
- Effective networking with relevant CBOs and FBOs as well as traditional healers and community leaders, with particular emphasis on community empowerment, poverty alleviation, and orphan care (see Chapter 37: Partnerships and Collaboration)
- Professionally supervised and trained lay community members, employees, and volunteers, to provide the bulk of hands-on care
- A 'caring for caregivers' component (see Chapter 20: Care and Support for the Carers)
- Bereavement support and followup (see Chapter 17: Loss, Grief, and Bereavement and the paediatric Chapter 30: Loss, Grief, and Bereavement in Children)
- Programme monitoring and evaluation (see Chapter 39: Monitoring and Evaluation)

Training

It is essential that community caregivers receive proper training to equip them to provide a high standard of care (see Chapter 38: Training, Mentorship, and Supervision).

South Africa: In South Africa, this training is in the process of being standardized. The South African Qualifications Authority (SAQA) Act has created a new framework for education and training. By receiving accredited SAQA training, home-based care workers will, in due course, have access to a career path (Cameron, 2003).

Transference of Skills

From professional to nonprofessional staff:

The mainstay of many successful grassroots African programmes is the transference of skills to lay community caregivers. They are trained to perform tasks usually assigned by qualified professional members of the interdisciplinary team and are supervised by a professional nurse. Given the lack of trained health care workers in SSA, this is a vital aspect of health care programmes. The time has now come to also consider ways of transferring these skills to the broader community and training experienced lay caregivers to assume a supervisory role. In the interests of balancing coverage with quality care in this scenario, minimum standards must be complied with and monitoring and evaluation should become the norm rather than the exception.

From rehabilitation professionals to nurses:

In SSA, rehabilitation health professionals (e.g., occupational and physiotherapists) are scarce, making it necessary for those who are available to teach their skills to the nurses who are taking responsibility for patients. There are simple, cheap locally-made aids that can really improve the quality of life of a disabled person and their carer.

From doctors to nurses and clinical officers:

In all African countries, doctors are scarce but are also the only prescribers of certain drugs, including morphine. For people in all communities to have access to effective pain management, nurses and clinical officers need to be trained and certified to prescribe morphine (see Chapters 4: Pain Management and Chapter 36: Drug Policy). This has been made possible in Zimbabwe as well as Uganda, where nurses and clinical officers with a 9-month course in palliative care can now prescribe morphine. However, the rate of practical training means the prescribing pool will increase very slowly.

Professional Supervision

People selected from the local community are trained as community caregivers. These caregivers live and work in the community and are the foundation on which home-based care programs are built.

Trained caregivers must be professionally supervised. This hones their skills and empowers them to demonstrate and teach basic hands on quality care to the family and immediate neighbors. Professional supervision ensures that patients receive adequate clinical care including pain and symptom control, effective management of OIs and appropriate referral.

The role that home-based care will play as antiretroviral drugs become more available in grassroots communities has yet to be defined. This recent development does, however, further accentuate the need for the professional supervision of community caregivers. Professional supervision is also necessary for the sake of the caregiver and forms the foundation on which the provision of care for the caregiver is based.

Caring for Caregivers

If caregiver burnout is to be prevented, it is crucial for a 'caring for caregiver' component to be included in HIV/AIDS programs, in particular home-based care. Home care programs in SSA serve poor communities whose members are coping with an excessive quantity of loss and grief. This stressful working environment is typically aggravated by a lack of adequate welfare infrastructure and referral options. Caregiver stress is compounded when clients are predominantly young adults and children with whom the caregivers identify. Chapter 20: Care and Support for the Carers provides interventions that programmes should establish to support professional and nonprofessional staff, volunteers, and family carers.

In the case of multi-program organizations, it may be possible to rotate community caregivers through an inpatient or training department. This can give them temporary reprieve from their traumatic working environment and provide an opportunity for personal and job-related growth and development.

Volunteers

Most palliative care programmes in SSA cannot survive without volunteers from the communities to supplement the services of paid staff. Volunteers get inspiration from training programmes and are motivated by trainers from other programmes that have standards applicable to the local cultural and social conditions and needs. Thus, training is heavily linked to promotion of palliative care throughout the communities in Africa.

While volunteers are vital in providing care in SSA, it is both unrealistic and unethical to expect impoverished people from resource-constrained communities to work without some kind of incentive. Stipends for travel and meals are commonly provided to volunteers, but the time has come to also give serious consideration to linking HIV/AIDS service delivery to job creation.

Volunteering is not limited to the provision of direct care to patients and families. At the local level a variety of support services are frequently provided by groups and individuals. The hospice board of directors, for instance, is composed of community leaders and businessmen who give their services voluntarily to promote the aims of an organization with which they identify. Many programs in SSA are blessed with regional and/or international partners who are also volunteers (see Chapter 37: Partnerships and Collaboration). In a similar vein, universities may provide free educational opportunities or donate faculty time in training courses organized by the local hospice.

Poverty Alleviation and Orphan Care

In SSA, aspects of community development and poverty alleviation are invariably interwoven into the delivery of community-based care. For example, few countries have social services geared towards the needs of the sick or the carers. Thus the family depends on the extended family for financial security in a crisis. Often the bread winner is the patient or the carer and this leaves the rest of the family in a crisis for school fees or for food. Although difficult to sustain, some programmes set aside small funds to meet these essential social needs for their clients. Such funds are often distributed from the nurses in the programme. There is also often a need to plan for the care and placement of orphans and vulnerable children. Staff should have up-to-date knowledge on services for vulnerable children as well as the availability and criteria of welfare grants, if any apply in their country.

This need for holistic care creates unique challenges as well as unique opportunities. Improving quality of life is one of the primary tenets of palliative care. An ongoing challenge facing CBOs is maintaining focus in the face of the vast array of basic needs that are encountered on a daily basis. Another is the issue of sustainability, and whilst this can never be guaranteed in the African context, it is important to perform a careful risk assessment before raising community expectations by embarking on a service that has little hope of being continued. When working in this environment, it can be difficult for organizations providing care to retain the necessary focus on their core business.

Networking With Other Services

Many of the holistic aspects of support cannot easily be taken on by the palliative care team, such as orphan care and school fees. In this case, there must be networking with and links to all organisations in the community that provide needed services.

Traditional Medicine

There is a rich diversity of culture and language across the African continent. Ritual and custom fall into the enshrined domain of traditional healers, who are in the main, more abundant and far easier to access than western health care professionals. Including them in the programme as networking partners is one way of ensuring that people living with HIV/AIDS and their families receive culturally sensitive care. This also provides the opportunity of learning about traditional and herbal remedies, many of which have been used over centuries.

Links Between Care and Prevention

Linking home-based care to HIV/AIDS prevention has been a significantly satisfying prospect for HCWs, who are able to teach infection control and encourage and support patients with HIV/AIDS in regard to divulging their status. They also capitalize on the many powerful teaching moments which present when the silence has been broken and the disease can be openly spoken about. Noticeable stigma reduction occurs when all the health care providers in both the formal and informal sectors as well as community leaders model the respectful care given to people living with HIV/AIDS in the home. It is likely that, in the future, caregivers may be in a position to link care to treatment and that this will be even more satisfying and far reaching.

References

- Cameron S. 2003. Training community caregivers for a home-based care programme. In: Uys L and Cameron S, eds. *Home-based HIV/AIDS Care*. Cape Town: Oxford University Press Southern Africa.
- Defilippi KM. September, 2002. Continuum of care. Presentation at first South African National Home-Community-Based Conference, *Khomanani – Reaching Out – Scaling Up*. South African National Department of Health; HIV/AIDS/STIs/TB Chief Directorate; Treatment, Care and Support Sub-Directorate.
- Defilippi KM. 2003. Implementing integrated community-based home care. In: *Home-based HIV/AIDS Care*. Uys L and Cameron S eds. Cape Town: Oxford University Press Southern Africa.
- Harding R, Stewart K, Marconi K, O'Neill JF, Higginson IJ. 2003. Current HIV/AIDS end-of-life care in sub-Saharan Africa: a survey of models, services, challenges and priorities. *BMC Public Health*. 3:33.
- Kikule E. 2003. A good death in Uganda: survey of needs for palliative care for terminally ill people in urban areas. *BMJ*. 327:192–194.
- Sepulveda C, Habiyambere V, Amandua J, et al. 2003. Quality care at the end of life in Africa. *BMJ*. 327:209–213.
- Uys LR. 2001. The implementation of the integrated community-based home care model for people living with AIDS. *Africa Journal of Nursing and Midwifery* 3:34–41.
- Uys L. 2003. A model for home-based care. In: Uys L and Cameron S, eds. *Home-based HIV/AIDS Care*. Cape Town: Oxford University Press Southern Africa.
- WHO/UNAIDS. Sep 2000. Key elements in HIV/AIDS care and support. Draft working document.