

Training, Mentorship, and Supervision

Overview

For palliative care to become available throughout the region, individual countries need to establish governmental policy, education, and drug availability—the foundation measures needed for an effective palliative care programme (see Chapter 35: Role of Government and Chapter 36: Drug Policy). Education and training are therefore vital aspects in the implementation of an effective palliative care programme. Providing high quality palliative care for all people living with HIV/AIDS requires improved training of health and community workers as well as general health education. Much of the HIV/AIDS training delivered in the past has been concerned with transmission and prevention. In many countries there has been little emphasis on training for care, although this is changing and the focus is shifting to areas such as palliative care (UNAIDS, 2000).

Palliative care providers in the region face many challenges, including the lack of education of those providing the care (McCaffery, 1992) both at the professional and lay levels. Education is a priority and training needs to be provided for health care workers in hospitals and the community, teachers, and religious and community leaders. These people can then train community health workers, volunteers, and the family (UNAIDS, 2000). Training needs to be delivered in a culturally sensitive manner that is accessible to different segments of the population (Foley, 2003).

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Who Should Be Trained?

Palliative care uses a multidisciplinary team to provide care and relies on every member of the team being able to play their part. This may include doctors, nurses, pharmacists, social workers, pastors, community-based home-care workers, volunteers, and traditional healers, all of whom therefore need appropriate training in order to provide care (Foley, 2003).

Health Care Professionals

All health care professionals require some training in palliative care in order to give effective care (Munudawafa, 2001). Training should be at both the pre-registration and post-registration levels, available to both specialists and generalists, and be able to be given in many different ways. The World Health Organisation (WHO) has challenged medical training institutions to ensure that palliative care is:

- Compulsory in courses leading to the basic professional qualification
- Accepted as a suitable subject for testing by the exam boards
- Recognised by universities and professional bodies as an appropriate subject for study, dissertations, certificates, diplomas, and advanced degrees
- Included in postgraduate programmes of continuing professional education
- Recognised as an appropriate subject for scholarships, fellowships, and grants by academic institutions and research-funding bodies (WHO, 1990)

People with different backgrounds need to collaborate and work together as a team in providing palliative care. Teams function best when team members understand and respect one another's ideas and perspectives. Multiprofessional, or interdisciplinary, education is one way to achieve this. However, this is a new concept for many within the region and there is a long way to go before it is a reality. The division between nurses and doctors is so great in some countries that many would find it hard to undertake a course that both were attending.

Experiences from many countries suggest that palliative care training should and indeed can be incorporated into existing health care system training programmes (Stjernsward, 1998; Foley, 2003). Palliative care education should be systematically included in pre-registration programmes for all health care professionals as it needs to be an integral part of their training. Student nurses must be equipped with theoretical and practical knowledge that allows them to function and initiate change in their clinical environment (Wouters, 1994). This is true for all health care professionals as palliative care is not only the prerogative of specialists; most nurses and doctors will provide palliative care regardless of where they practice (Sheehan, 2001).

The burden of disease in sub-Saharan Africa is such that no health care worker will escape caring for someone needing palliative care due to HIV/AIDS alone, regardless of other illness requiring such care. It is therefore vital that education for palliative care should begin in the pre-registration training schools and continue through in-service training and continuing education. Only a small number will go on to be specialists, but all need to have a basic understanding of the principles and practices of palliative care.

The important thing is not that all health care workers specialise in palliative care, but that palliative care training is available at various academic levels to fit in with the varying needs and requirements of the different professions (Jodrell, 1998). Training also should reach beyond health care workers, to patients, families, and carers. Health care workers, especially nurses, need to be able to facilitate it.

Family and Voluntary Caregivers

In rural settings palliative care relies heavily on families and voluntary caregivers. They must be given appropriate and culturally sensitive training to provide effective palliative care. It is important that training programmes be grounded in reality and not be over-ambitious or raise unrealistic expectations. The extent of the training needs to be proportional to the roles and responsibilities an individual is undertaking (Cummings, 1998). Following training, supervision of volunteers is vital to ensure that they are giving appropriate care. Training can be given by hospices and other healthcare organisations, but ideally is provided by the organisation that will be working with and supervising the volunteers. Those providing supervision invariably need additional training to supervise effectively.

Traditional Healers

Traditional healers need palliative care education because they are potential resources for disseminating palliative care information and will be involved in the care of people who need palliative care. In Mozambique, Zimbabwe, Uganda, and South Africa, government-sponsored education of traditional healers has sought to increase effective palliative care and symptom control awareness. For example, in KwaZulu Natal a collaboration between the AIDS Foundation and traditional healers resulted in the development of a training curriculum to increase the impact of HIV/AIDS prevention, education, and management (Jones, 2001).

The Public

Palliative care education should be available at all levels, including the family, community, and national levels. Community and religious leaders, legislators, government officials, and policymakers all need education about the essential components of palliative care. They need to know how and where it can be provided, which will ensure there are effective supporters and advocates at all levels. The public must be made aware of the following information:

- Palliative care will improve a patient's quality of life.
- Treatments exist that can relieve pain.
- Patients do not have to suffer prolonged intolerable pain or other distressing symptoms.
- Drugs for the relief of pain can be taken indefinitely.
- The medical use of morphine does not lead to abuse and addiction does not occur when morphine is taken for pain control (Stjernsward, 1998).

What Should Be Taught?

Two-Phase Approach to Palliative Care Training

The WHO suggests a two-phase approach to providing palliative care training in developing countries (MacDonald, 1998):

Phase One: Basic education programmes in palliative care that can be introduced anywhere and should be within the capacity of any country whose government is making the development of palliative care a reasonable priority. Elements of this programme include:

- The distribution of teaching resources
- Training workshops
- Curriculum review
- Local training courses
- International fellowships
- Family teaching
- Networking on a regional and international level

Phase Two: Development of specialist palliative care training centres in core countries that have a national policy on palliative care, give top priority to palliative care and education, and are successfully implementing Phase One programmes.

The region still has a long way to go to develop this coordinated approach. It is equally important to develop training programmes at the undergraduate level and to provide continuing education to the large number of qualified health care workers. A large number of specialists and generalists already are gatekeepers for palliative care (Scott, 1998). They need to be educated about the philosophy of palliative care and its relevance beyond terminal disease, as principles applied early in the illness trajectory can reduce pain and suffering later on. They also are a key group to be trained in the use of morphine so that once it is available it is utilised properly.

Palliative Care Skill Sets

Training in palliative care focuses on six major skill sets (Foley, 2003):

- Communication
- Decision making
- Management of complications of treatment and the disease
- Symptom control
- Psychosocial care of patient and family
- Care of the dying

Areas of Learning

Multi-dimensional education in palliative care includes at least a minimum of learning in three important areas (WHO, 1990):

Attitudes, Beliefs, and Values

- The philosophy and ethics of palliative care
- Personal attitudes towards HIV/AIDS, pain, dying, death, and bereavement
- Illness as a complex state with physical, psychological, social, and spiritual dimensions
- Multiprofessional teamwork
- The family as the unit of care

Knowledge Base

- Principles of effective communication
- Pathophysiology of the common symptoms of advanced disease
- Assessment and management of pain and other symptoms
- Psychological and spiritual needs of seriously ill and dying patients
- Treatment of emotional and spiritual distress
- Psychological needs of the family and other key people
- Availability of community resources to assist patients and their families
- Physiological and psychological responses to bereavement

Skills

- Goal-setting in physical, psychological, social, and spiritual dimensions
- Development of a family care plan
- Monitoring of pain and symptom management

Training Models

Palliative care training should be made available in a variety of forms across sub-Saharan Africa. Courses need to be flexible and relevant to local needs and the environment. Training should also take into account the situations in which individuals are working and the resources available to them. The palliative care training models that should be available include conferences, self-study programmes, computer and web-based approaches, face-to-face taught programmes, and clinical placements (Sheehan, 2001). All classroom training that is focused on the provision of care should be combined with an appropriate clinical learning experience.

Distance Learning

Palliative care expertise is spread thinly throughout the region, with some countries having almost no palliative care expertise. Distance learning programmes can ensure that palliative care training is available to clinicians throughout the region. Such programmes will increase the education coverage in the region and help remove barriers that can prevent access to education—such as limited availability of qualified professionals to run courses and the cost of travel within the region. Distance learning describes an educational delivery system that has been planned on the basis of wide geographical separation of the education provider and the student (Quinn, 1995). The concept permits different ways to run the courses. Some programmes may have no face-to-face contact at all, whereas others may have some face-to-face contact supplemented by distance-learning materials.

Most distance-learning programmes today are conducted through the Internet. Students can download materials from the Internet and be in contact with their tutor via e-mail. This works well in areas where Internet access is well developed, but this is not the case in many parts of Africa, especially rural settings. In these areas it is possible to use CD-ROM or paper-based materials, although this may require running the course over a longer period of time as postal services can be slow. In most courses, students are sent reading materials, allowing even students who do not have access to a good library to pursue distance-learning programmes. This is helpful since even university libraries often do not contain many of the palliative care texts and journals.

Face-to-Face Programmes

Distance-learning programmes need a lot of motivation on the part of the student as they often work on their own, far from other students or tutorial support. Some people, whilst motivated, may find it hard to complete such a programme and value the face-to-face contact with other students and lecturers. Thus, there is still a place in Africa for the more traditional face-to-face courses. They may be modular programmes for those wishing to specialise in the area or short courses ranging from one to four weeks in length. They may be conducted at the regional or national level, though it is likely that travel costs would prevent regional participants from attending modular programmes.

Clinical Placements

It is hard to teach palliative care without the student spending time in the clinical setting. Students need to be able to observe and participate in patient care in order to strengthen and utilise the knowledge they gain (Scott, 1998). Clinical placements are a fundamental education strategy in health care education. Within the palliative care context they should cover a wide variety of settings such as hospitals, the community, day care, and home-based care teams. They may be undertaken in new areas or in a student's current clinical area. Because exposure to experience does not necessarily mean that learning will take place, students need help to learn through the development of appropriate aims and objectives and support from skilled practitioners and educators (Quinn 1995). They also need a clinical environment conducive to learning, which may be a challenge for some students within the region. Because specialised units often admit patients late in the disease process, students also need alternative placements where they can see patients earlier in the disease process (Scott, 1998). Resources in specialised units may also be resource rich compared to 'back home', and students may need help to apply what they have learnt to their own settings.

Specialist Training

The United Kingdom was the first country, in 1987, to recognise palliative medicine as a speciality. For the same to happen in African countries, it needs to be accepted by patients, the public, and health care workers (Calman 1988). The main goal of a specialist training programme is to train health care workers to function as specialists in palliative care. There are some courses in Africa, such as the master's degree in palliative medicine in Cape Town, and the specialist course for nurses and clinical officers in Uganda (see Appendix 1: Resources). But public education and political advocacy are needed alongside the development of such programmes to promote acceptance of the specialists once they are trained.

Other Models

Other models of training can be used effectively within the palliative care context. These include:

- Lectures
- Ward rounds/case conferences
- Conferences
- Journals: The current lack of palliative care literature within sub-Saharan Africa needs to be remedied, such as through the recently launched *APCA Journal of Palliative Care* (see Appendix 1: Resources).
- Reflective practice: While reflection has been used traditionally in the fields of nursing and counselling, it is a key way of learning within the palliative care context and should be applied across the broad spectrum of health care professionals (Atkins, 1993).
- Videos, drama, and music: These are especially important when training is focussed at the community and volunteer level, where some of the students may be illiterate or not used to formal education settings (Foley, 2003).

Supervision and Mentorship

Appropriate supervision and mentorship are vital elements of any palliative care training programme. Supervisors and mentors have a vital role in helping students learn and making them feel supported and encouraged. The role of a supervisor is to 'facilitate personal and professional growth in the supervisee and to provide support for the latter's development of autonomy' (Faugier, 1992). According to the English National Board for Nursing, Midwifery and Health Visiting (ENB, 1993) a supervisor is an appropriately qualified and experienced nurse (health care worker) who is trained to oversee students' practice to ensure that the students receive relevant experience to achieve their learning outcomes and develop competencies. The supervisor's role is a formal one and is normally included in the individual's managerial responsibilities.

At times, the terms 'supervisor' and 'mentor' have been used interchangeably without consensus as to their meaning (Quinn, 1995), although mentorship is often seen as more of a personal relationship between two people than a managerial one. However the terms are defined, both supervision and mentorship are important in the delivery of palliative care training. It is important for health care workers who are new in the field to have the supervision and mentorship of someone more experienced as they undertake clinical placements and as they set up services in their own clinical environment. As services develop, such mentors may not be in the same place or even the same country as the student. It is anticipated that as palliative care services become more available, mentors will be able to meet and work regularly with the students.

Monitoring and Evaluating Training Programmes

The effects of training are important to monitor and evaluate. Whilst evaluating educational programmes is often challenging, this is particularly true for palliative care training due to the complex nature of the philosophy being taught (Sheehan, 2001). Standard assessment and evaluation measures are therefore needed for clinical skills, decision making, and a broad range of physical, psychosocial, and spiritual care (MacLeod, 1993).

The development of standards for palliative care and training is an important step in the evaluation process. Whilst these exist in a few countries, such as South Africa and Zimbabwe, they do not exist in most countries in sub-Saharan Africa and there is no consensus as to region-wide standards. It is important to ascertain whether training programmes are 'fit for purpose' — that is, are

they producing the kind of practitioners that one has anticipated and what is the 'value added' of the training? The real importance of education lies in the value it adds to the student as a result of undertaking it (Quinn, 1995).

Monitoring and evaluation are important not only within each training organisation but also across different organisations. This allows comparisons of the quality and standards of programmes in different places and ensures that similar courses are of a similar standard. It is anticipated that in the future the African Palliative Care Association (APCA) will play a role in both setting standards for palliative care education across the region and in the monitoring and evaluation of the training programmes (see Chapter 41: Palliative Care Associations).

Training Challenges in the Region

Because palliative care is still an emerging field in Africa, regional training in palliative care has not been clearly defined or agreed upon (Jodrell, 1998). Nevertheless, education of care providers can improve overall care (Field, 1997). Key measures include:

- Conferring a basic level of competence in palliative care in all practitioners
- Developing expected levels of palliative care skills considerably beyond this basic level
- Establishing a cadre of professionals to develop and provide exemplary care, and to generate new knowledge

Palliative care education programmes vary widely throughout the world. Africa faces many challenges in providing and developing appropriate training, including:

- Integrating palliative care content into an already packed curriculum for pre-registration training
- Increasing the knowledge of faculty members in palliative care so that they see its importance and include it in the curriculum
- Ensuring that palliative care training is not only didactic but pays attention to students' values, beliefs, personal experiences, and culture (Sheehan, 2001)

- Identifying methods not only to increase knowledge and skills but also to enhance compassion, empathy, and the existential aspect, or 'art', of palliative care (Hanson, 1995; Sheldon, 1996)
- Basing palliative care training on national policies and programmes that do not yet exist in many African countries
- Training enough palliative care providers to keep up with the growing demand for services for people who are dying with unrelieved suffering without palliative care services (Scott, 1998)
- Funding for programmes
- Changing the philosophy of medical education from its focus on diagnosis, investigation, and cure without relief of suffering and the perception that the death of patients is a failure
- Developing political support for palliative medicine/care in the academic world, providing a firm academic base and a clear recruitment strategy
- Educating the public and government about the need for palliative care and, hence, palliative care training to create a more supportive environment
- Establishing standards for care and training within the region

The Way Forward

The future is exciting for palliative care training in sub-Saharan Africa. The scope for development is great as more people recognise the need for and provide training throughout the region. A November 2002 meeting in Cape Town of palliative care trainers from the region was a significant step in the development of training and for networking and commitment to palliative care in the region. The Cape Town Declaration was signed by 28 people representing eight countries, and showed a commitment to the development of palliative care training in Africa (see Box 38.1). The African Palliative Care Association (APCA) was formed out of this meeting and will play a significant part in the development of palliative care training and standards in sub-Saharan Africa (see Chapter 41: Palliative Care Associations).

Recommendations to consider for palliative medicine education as we look to the future of palliative care training in sub-Saharan Africa include (Scott, 1998):

- Set standards and make recommendations for the development of palliative care education at a regional or international level, including learning objectives and core components.
- Tap the resources of the several 'academic' centres of palliative care in the region, where faculty members are experienced in and committed to the development of palliative care across a wide range of disciplines. Once recognised, these centres can not only demonstrate quality palliative care but also focus on the methodology of palliative care education in the region, learning resources, effective evaluation, etc., and be committed to working with each other across the region.
- Focus on community patterns of practice and practitioner behaviours, and develop guidelines that are culturally and socially appropriate.
- Ensure that training programmes select the most appropriate learners who will have the largest impact on the burden of suffering in the population. This is important where resources are limited and a balance needs to be reached between the training of specialists and generalists, both of which are important.
- Develop and recognise a career structure for palliative care professionals of different disciplines and encourage them to further develop palliative care.
- Establish a strong research base for palliative care across sub-Saharan Africa in which researchers from different countries work together to provide a region-wide evidence base.
- Advocate for political commitment at the national and regional levels to ensure the provision of appropriate resources, such as drugs, to support the provision of quality palliative care.
- Collaborate with governments, universities, non-governmental and private organisations, and charities to develop palliative care training.

Box 38.1:***The Palliative Care Trainers Declaration of Cape Town – 13th November 2002***

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness. This includes prevention and relief of suffering by means of early identification and effective assessment and treatment of pain and other problems, physical, psychosocial, and spiritual. It uses a multi-disciplinary team approach to address the needs of patients and their families, including dignity in dying and bereavement support. Palliative care has only recently been recognised in Africa which has a great need. It is therefore an essential component of health care in Africa today in the light of the epidemic of HIV/AIDS and increasing cancers. The provision of palliative care requires policy, drug availability, funding, and education, focused on the patients and family and integrated into the existing health services and the continuum of care. The first meeting of palliative care trainers in Africa was held in Cape Town. Thirty participants attended from five African countries – Kenya, South Africa, Tanzania, Uganda, and Zimbabwe – along with representatives from the World Health Organisation and the Diana Princess of Wales Memorial Fund.

At the end of the meeting the group made the following declarations:

1. Palliative care is a right of every adult and child with a life-limiting disease. Therefore palliative care should be a part of national health care strategies making it accessible and affordable for all in Sub-Saharan Africa.
2. The control of pain and symptoms is a human right and therefore appropriate drugs should be available in every country in sub-Saharan Africa as part of the essential drug list, including opioids such as morphine. These drugs should be available and accessible at all levels including the community
3. In order to provide good quality palliative care, all members of health care teams and care providers need training. It is therefore crucial to establish training programmes at all levels i.e. under- and post-graduate, pre- and post-registration, for community workers, carers and volunteers. This should be provided for all members of the multi-disciplinary team providing care.
4. Palliative care should be provided at all levels — primary, secondary, and tertiary. This necessitates a career structure for all those specialising in palliative care and in the integration of palliative care at the university and national departmental level in each country.

This group has dedicated itself to support the promotion of palliative care and training throughout Africa. Collaboration will be enhanced through the establishment of the African Palliative Care Association (APCA).

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