

## Chapter 41

***Palliative Care Associations******Overview***

The concept of palliative care is dynamic, changing, and relatively new in many African countries. It values teamwork, recognising that no individual can meet all the needs of a person who needs palliative care. It requires collaboration and respect for each other as members of a team. We have limited impact as individual health care professionals or organisations in advocating for the further development of palliative care within our countries and region. But we can achieve a lot more as a group of professionals or organisations working together at regional, national, and international levels. This is why palliative care associations are central to the development of palliative care services within a region.

This chapter explores the role of palliative care associations, their values, and issues around setting up associations. It offers two case studies of palliative care associations in South Africa and Uganda, then discusses the development and purpose of the African Palliative Care Association. See Appendix 1 for information on how to contact specific associations.

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## The Role of Palliative Care Associations

There are many palliative care associations throughout the world. Some are national-level, such as the Canadian Hospice Palliative Care Association and the Palliative Care Association of Uganda. Others are regional, like the Asia Pacific Hospice Palliative Care Network (APHPC), the Eastern and Central Europe Palliative Care Taskforce (ECEPT) and the African Palliative Care Association (APCA). The association's specific roles and responsibilities vary according to the region they serve, the resources available in the region, and the development of palliative care in the region. There are nevertheless some key roles that cut across all palliative care associations — including education, networking and support, setting standards, advocacy, and publications.

### *Education*

Education is key to the development of palliative care within the African region. Whilst it remains a new concept in many countries, it is well established in others, including South Africa, Zimbabwe, Kenya, and, more recently, Uganda. Palliative care associations have an important role to play in developing education programmes and ensuring that these programmes are 'fit for purpose' — that they train health care professionals to a level of knowledge and skills that equips them to provide palliative care within their setting.

For some individuals, this training may be to a very high level of skill and knowledge that enables them to function at a specialist level. Examples of training include the Clinical Palliative Care Course for nurses and clinical officers in Uganda, the Master's in Palliative Medicine for doctors in South Africa, the Higher Diploma in Palliative Care in Kenya, and the newly accredited BTech in Palliative Nursing, also in South Africa. For others, the training may be at a more general level that enables them to integrate palliative care services into their wider role.

Whilst it is not the role of the palliative care associations to actually run these courses, it is their role to ensure that they develop practitioners to the required level and that they meet minimum standards for training.

On a more general level, some palliative care associations may conduct regular palliative care update days as part of an ongoing continuing medical/nursing education programme. These may be run at the regional or national levels or even at the local level. For example, the Palliative Care Association of Uganda runs national update days every quarter, addressing key issues in palliative care as identified by team members, such as pain control for children or psychosocial issues. These updates are also run, more recently, at the local level in different parts of Uganda, such as Mbarara and Hoima. Members of the Association are encouraged to attend these update days where possible. The updates give them a chance to keep up with current issues and to meet with others to discuss the issues and challenges they may be facing.

Associations also have a role in disseminating information to their members on different training programmes. This may include in-house programmes run by the different palliative care/training institutions or those taking place in the region and internationally. Where the palliative care association has been in existence for some time, there may be opportunities for funding and scholarships to attend such trainings, but this will vary among associations. It is important for associations to try to develop this area where possible.

### Networking and Support

Networking is the process by which two or more organisations and/or individuals collaborate to achieve common goals (International Council of AIDS Service Organisations (ICASO), 2002). Networking is a vital function of palliative care associations (see Box 41.1). The palliative care association is an important forum for members to meet and share ideas, challenges and best practices amongst themselves. It is also a good place to meet with potential donors and departments of health and welfare. According to ICASO, the ethical, technical and managerial demands of HIV/AIDS are on such a scale that they can only be addressed by cooperating as much as possible.

**Box 41.1:**

#### Networking

ICASO defines a network as:

- A group of organisations/individuals who come together to pursue joint goals or common interests
- A venue for social action through exchange and mutual learning
- Sustained through some form of communication
- Committed to a jointly developed structure and shared responsibility
- Based on member ownership and commitment to shared objectives and means of action

Source: ICASO, 2002.

There is great need for palliative care within the African context. By working together as a network through palliative care associations, it will be possible to have a greater impact, both at the national and the regional levels. This networking is important for different organisations working within the palliative care contexts, and for individuals working in isolation who are trying to develop the services in their area. The palliative care association is able to bring together in one professional body all health care professionals interested in palliative care, enabling them to share knowledge and experience and to provide support for each other.

### Setting Standards

It is important to set and recognise standards for palliative care within countries, when initially developing services and when the services become more established and widespread throughout the country. Palliative care associations are ideally positioned to set and monitor guidelines and standards for palliative care within their context. These will include local standards that apply to palliative care organisations, such as standards for staffing, clinical care (e.g., pain control), and philosophies of care. Associations also may be able to contribute at a higher level to setting appropriate government standards for palliative care and facilitate the monitoring process for these standards (Pahl, 2003).

Setting standards is an evolutionary process. As the palliative care services are developed, the standards may need to be modified to meet the needs at that time. It is also important to recognise that whilst core standards may be transferable between countries, it will be necessary to adapt standards so they are appropriate to the culture and health care setting in the different countries.

Palliative care associations have an important role to play in developing services for both adults and children. As a guideline they can assist individuals to develop services and can help to manage and improve performance, secure resources, and bring legitimacy to organisations working within the palliative care context (Pahl, 2003). This legitimacy is enhanced if these standards are seen to have come from a recognised national or regional body, such as a palliative care association, made up of representatives from different organisations who are working together to develop palliative care services.

It is also important that as these standards are developed they are adopted by the palliative care association involved, by the individual organisations, and by the government. This will enable all interested parties to work together to ensure that the standards are adhered to and monitored.

### ***Advocacy***

The advocacy role of palliative care associations should occur at many different levels, from the community level to the national level, even at the international level. Palliative care associations have a mandate to promote palliative care in the local community by mobilising and enabling health care professionals to impart knowledge to the community and the media, such as on the safe use of morphine. They also must advocate for the availability of palliative care drugs for all in need, and for affordable and appropriate palliative care to be incorporated into the whole spectrum of health care services. At an international level, the associations can advocate with international organisations, such as the World Health Organisation, for palliative care within the global context. It is important that national and regional palliative care associations come together with one voice so they can have a greater impact in this area, since palliative care is not well represented or understood within the international context.

### ***Publications***

Most palliative care associations have some type of publication, whether an informal newsletter or a peer-reviewed journal. These publications provide important forums for exchanging and disseminating information and research and sharing best practices. They are also tools for communicating information about research projects, training programmes, and funding opportunities, and are important in the associations' overall communications and advocacy efforts. As associations develop, these publications may take on a more sophisticated role. For example, with appropriate support and funding, it is hoped that the *APCA Journal of Palliative Care* will develop into a well-recognised and peer-reviewed journal, through the African Palliative Care Association.

### ***Other Roles***

Some associations may play other roles besides those described above. For example, the Hospice and Palliative Care Association of South Africa (HPCA) is very involved in fundraising and ensuring support for hospices within the region. Most of the hospices are now run by non-governmental organisations that rely on external funding for their survival (Gwyther, 2003a). Other associations may not be in this position. It is therefore important to recognise that whilst palliative care associations have key roles, each one will work within its unique context and needs to develop its unique way.

## Values of Palliative Care Associations

A 2003 meeting in The Hague brought together individuals working within national and regional hospice and palliative care associations from 23 countries (Clark, 2003). Participants discussed issues around 'values' for national and regional associations. These values were set within the context of the 2002 World Health Organisation definition of palliative care (see Box 41.2). Delegates identified three main areas of the values that guide hospice and palliative care. Each area includes imperatives that support the overall provision of hospice and palliative care, as follows:

### Box 41.2:

#### **World Health Organisation Definition of Palliative Care**

Palliative care is the active total care of patients whose disease is not responsive to curative treatment. Control of pain, other symptoms, and of psychological, social, and spiritual problems is paramount. The goal of palliative care is to achieve the best possible quality of life for patients and their families. Many aspects of palliative care also apply earlier in the course of the illness, in conjunction with anticancer or antiretroviral treatment. Palliative care:

- Affirms life and regards dying as a normal process
- Neither hastens nor postpones death
- Provides relief from pain and other distressing symptoms
- Integrates the psychological and spiritual aspects of patient care
- Offers a support system to help patients live as actively as possible until death
- Offers a support system to help the family cope during the patient's illness and in their own bereavement.

Radiotherapy, chemotherapy, and surgery have a place in palliative care, provided that the symptomatic benefits of treatment clearly outweigh the disadvantages. Investigative procedures are kept to a minimum.

Source: Sepulveda, 2002.

#### **Stakeholders and Relationships**

- Promote palliative care to other relevant national bodies.
- Share information in an open way with each other.
- Involve service users (patients/carers) in developing services.
- Facilitate creativity and empower change
- Reflect the views of individual hospice and palliative care providers.

#### **Partnership/team values**

- Value multi-disciplinary teamwork and volunteers.
- Lead by example through high standards of work.
- Foster mutual respect and integrity among service providers.
- Establish and promote partnerships based on trust and exchange.
- Value care for the caregiver.

#### **Core values and attitudes**

- Respect each individual's faith, belief system, and culture.
- Respect every individual regardless of sex, age, race, intellectual or socio-economic standing.
- Recognise that the individual and family are entitled to make informed decisions about care and end-of-life care.
- Respect the confidentiality of all information arising out of the provision of care.
- Believe in empowering the individual, the family and the community.

## Setting up a Palliative Care Association

Every palliative care association has to start from somewhere. Usually it is a group of individuals or organisations involved in palliative care that get together to share ideas and network together and then decide to form an association (see Box 41.3). When forming an association it is important to get as many of the stakeholders involved in the delivery of palliative care from the start as this will encourage ownership of the association.

Due to the number of palliative care associations already in existence it is not necessary to start from scratch with aims, objectives, and constitutions. Most palliative care associations will be more than happy to share their aims and objectives along with copies of their constitutions. These will then need to be adapted to fit the context of the new association being set up.

It is important that all palliative care associations become officially registered, whether as a charity or a non-governmental organisation with a proper constitution, depending on the rules and guidelines of the countries involved. It is also important that they network with other organisations. Where there are regional associations it is important that they join the regional organisation and link with other organisations as appropriate.

### Box 41.3

#### **A New Palliative Care Association Should Address:**

- Balance between stakeholder demands and priorities
- Balance of democracy and expertise when choosing the committee
- Need to ensure that an appropriate structure is developed and that the association is 'fit for purpose'
- Need to ensure clarity about the mandate of the association
- Need to have an effective and reliable funding source
- Need to be visionary and philosophically provocative
- Need to have clear and dynamic leadership

*Source: Prall, 2003.*

### Examples of National Palliative Care Associations in Africa

#### *The Hospice and Palliative Care Association of South Africa (HPCA)*

HPCA was begun in 1987, following the development of the first hospices in South Africa in the early 1980s. The association is dynamic and has changed and developed over the years to meet the palliative care needs within South Africa. The HPCA's objectives are to advocate for palliative care, support member hospices, develop community services, communicate and share information among members, and network with care agencies, funders, and departments of health and welfare (Gwyther, 2003b).

HPCA is registered as a not-for-gain company which operates through a number of sub-committees and a national advocacy officer, thus minimising the administrative structures and costs. The sub-committees include the Fundraising and Public Relations Committee, the Organisation Development Committee, and the Patient Care and Education Committee (Gwyther, 2003b).

The association has been widely involved in developing and supporting education programmes in palliative care for a variety of care providers, including nurses, community workers, and doctors. The association also has its own development fund that focuses on capacity development and collaboration between member hospices, along with a mentorship programme which is funded by the Open Society Institute and is part of the association's programme of research and development activities.

#### *The Palliative Care Association of Uganda (PCAU)*

PCAU was set up in 1998, with the aim of maintaining standards, bringing together key players and stakeholders, establishing a bi-annual journal, providing quarterly continuing medical education updates, and producing publications (Merriman, 2003).

PCAU initially was run out of Hospice Africa Uganda, but in 2003 the association was registered as an independent non-governmental organisation. PCAU was founded to help support and promote the development of palliative care and palliative care professionals in Uganda. It is made up of professionals from throughout Uganda who are interested in palliative care.

PCAU's objectives fall under five main areas:

**Education**, including providing quarterly seminars in palliative care, access to training programs in palliative care, disseminating information through the *PCAU Journal of Palliative Care* and other materials, and encouraging research on palliative care in Uganda.

**Support**, bringing together health professionals interested in palliative care to enable them to share knowledge and experience, and supporting palliative care association branches throughout Uganda.

**Promotion**, by mobilising and enabling health professionals to impart their knowledge to village residents and the media, identifying and training key personnel in villages who can care for the terminally ill and make referrals, and communicating with other palliative care groups within East Africa to encourage palliative care in countries that do not yet offer it.

**Setting standards** for palliative care in Uganda and registering all palliative care services in the country.

**Networking** with other organisations providing palliative care.

PCAU has met some of these objectives and is working out others. The association has a membership of more than 100, with around 60 attending the quarterly update days. Several district branches have been opened and update days are also being run at the district level.

### ***The African Palliative Care Association (APCA)***

APCA is a non-profit organisation that was registered in February 2003. APCA aims to improve the quality of life of patients with life-threatening illness and their families within Africa by promoting palliative care. The association was formed following a November 2002 meeting of palliative care trainers in Cape Town which was organised and funded by the Princess Diana Memorial Fund (see Box 41.4). Delegates attended from five different African countries, Kenya, South Africa, Tanzania, Uganda, and Zimbabwe. Following the meeting delegates from these countries formed APCA.

The association aims to promote the implementation of the enormous knowledge in palliative care; train those who, at any level, are involved with the care of the terminally ill and promote study and research; foster networking links between palliative care providers and patients' relatives and care givers; address the ethical problems associated with the treatment of the terminally ill; establish an inter-African and international network for the exchange of information and expertise; promote or sponsor publications or periodicals concerning palliative care; acknowledge and share achievements of already established programmes; and promote access to human and financial resources for emerging palliative care programmes that meet APCA criteria.

The association's objectives are to promote standards for quality palliative care services for adults and children; advocate with governments for affordable and appropriate palliative care to be incorporated into the whole spectrum of health care services; promote the availability of palliative care drugs for all in need; encourage the establishment of national palliative care associations in all African countries; encourage sharing among such associations; promote training programmes suitable to African countries; and create standard guidelines for training at different levels.

Whilst the association is still in its infancy, it is hoped that it will develop into a strong network and have a role to play in the development of palliative care services within the African region. The association's first general assembly was held in Arusha in June 2004, when the *APCA Journal of Palliative Care* was launched. Two hundred people attended from 22 different countries within the region. An inaugural board of directors for the association was also elected with representatives from Ghana, Kenya, Nigeria, South Africa, Tanzania, Uganda, and Zimbabwe.

**Box 41.4:**

***Palliative Care Trainers Declaration of Cape Town***

The November 2002 meeting was a good opportunity to share and learn what is happening in the field of palliative care and training. It was clear there is a strong commitment to enhancing and developing palliative care and training within the region. The Cape Town Declaration was written and signed by all those present at the meeting to demonstrate this commitment. It is also intended as an advocacy tool that can be used when trying to develop palliative care services, with the government and other key organisations.

The Declaration states:

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 level.
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.

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