WPCA Policy statement on defining palliative care

Purpose	To provide clarification on palliative care
Author	Liz Gwyther, Eric Krakauer
Publication Date	1st June, 2009
Audience	Palliative care personnel, national governments, international organizations
Circulation List	Regional and National Associations
Summary	This policy statement clarifies the WHO definition of palliative care as it applies in different geopolitical and economic settings.
Contact Details	liz@hpca.co.za
Review Date	1st June 2010

Introduction

The Worldwide Palliative Care Alliance is a global network of organizations committed to the development of palliative care in order to improve accessibility and availability of palliative care services for people affected by life-threatening illness.

The Worldwide Palliative Care Alliance has identified the need to produce a policy statement on the definition of Palliative Care, in light of the fact that a number of organizations have produced their own definitions that reflect their perceptions of palliative care.

The WPCA endorses the World Health Organization's definition of Palliative Care[1] but recognizes that this definition requires some explanation in order to clarify the comprehensive nature of palliative care.

Summary of Recommendations

The WPCA recommends the WHO definition of palliative care which outlines the basic principles for the delivery of palliative care

The WPCA recommends that all governments:

- adopt the WHO definition of palliative care
- integrate palliative care into their country's health care system
- support and work in collaboration with the NGO sector in the delivery of palliative care

The Goal of Palliative Care

The goal of palliative care is to improve **quality of life** for people and family members affected by life-threatening illness[2]

Palliative Care is not limited to those suffering from specific diseases. In the WHO definition of palliative care for children, it is stated that the principles apply to paediatric chronic disorders and that palliative care should also be provided for children with life-limiting illness.

Many health care professionals and people, who could benefit from palliative care, view palliative care as being limited to care of the dying. Such a view results in referrals and access to palliative care being restricted for many people who could receive significant benefit from this care earlier in their illness. Palliative care can, and should be instituted, together with disease-modifying treatment such as anticancer therapy or anti-retroviral therapy, for people with significant symptoms or who require other support.

The WHO definition of palliative care emphasizes the focus on active living by using expressions such as "quality of life", "affirms life", "to help patients live as actively as possible".

Palliative care also provides quality care to people who are dying and support for their family members. The importance of care for the dying also needs to be recognized and promoted. Modern medical care has a strong bias towards curative medicine, with the result that patients for whom cure is no longer an option are often abandoned by the health system. Palliative care and hospices provide active management of symptoms in order to improve comfort and quality of life for the dying person, while offering support for them and family members during this period. All health care professionals, and communities in general, need to recognize that dying is a normal process. Support needs to be given to patients and family members throughout the dying process when curative or disease-modifying treatment for life-threatening illness is not possible or not desired.

There is no time limit for the delivery of palliative care, and since palliative care "is applicable early in the course of illness, in conjunction with other therapies that are implemented to prolong life", it should not be offered only when disease-specific treatment has failed. The control of symptoms and emotional and spiritual support are important at the time of diagnosis of a life-threatening illness as well as throughout the course of the illness and the person's death.

Palliative Care in different geopolitical, cultural and economic settings

Palliative care developed as a response to suffering. It is accepted "as a basic human right when curative care is no longer appropriate."[3] The organization and provision of palliative care has to be adapted to the country, culture and context if the needs of the person requiring care and their family members are to be met.

Place of care

Palliative care is provided wherever a person's care takes place, whether this is the patient's own home, a care facility, hospice in-patient unit, hospital, and outpatient or day care service. This is one of the major advantages of palliative care. People requiring palliative care do not need to travel to a centre to receive their care. Much palliative care is provided in the home, with only those patients requiring more intensive care being identified and admitted to an in-patient facility. This admission may be short term, allowing the patient to return home once symptom control is achieved, with continuing care being provided by the hospice or other home palliative care team.

Models of care

The following three examples of palliative care delivery are described in order to show the range of models of palliative care delivery that exist:

1) Edmonton, Canada Capital Health (Edmonton and area) developed a regional palliative care program[4] which includes an administrative office; family physicians and home care with nursing and other assistance at home; hospice palliative care units for in-patient care; a tertiary palliative care unit for specialist palliative care; a palliative care consulting service to support primary care staff and physicians in community and in the acute care setting (hospital or hospice in-patient facility).

2) Integrated Community-based Home Care[5] in South Africa. This model of care draws on hospice and community resources. Community members are trained in basic nursing, palliative care and counseling skills and are employed as home-based carers. Support and supervision of the home-based carers is provided by the professional nurse and there is access to the interdisciplinary palliative care team at the hospice. People requiring admission are referred either to the hospice in-patient unit or, if the hospice does not have in-patient beds, to the local hospital. Ideally hospital staff are trained in palliative care and hospice staff may visit the patient in the ward and provide a consultancy service.

3) The Neighborhood Network in Palliative Care[6], Kerala, India is a sustainable community-owned service capable of offering comprehensive long term care and palliative care to those requiring it. In this program, volunteers are trained to identify problems of the chronically ill in their areas and to intervene effectively, with active support from a network of trained professionals.

Other factors impacting on the delivery of palliative care

In resource-poor settings, the social circumstances of the person receiving care and their family members may be a major source of the patient's suffering and may need to be a key focus for the hospice or palliative care team. While palliative care may be viewed as a credible alternative to aggressive, often futile treatment, poor communities may view palliative care with suspicion, fearing that it is being provided instead of disease-specific treatment[7]. Palliative care should always be provided in conjunction with disease-specific care. Palliative care workers have a responsibility to advocate for disease-specific treatment, such as oncology treatment or anti-retroviral treatment, in areas where this is not yet available to patients. All healthcare professionals should be trained in primary palliative care in order to offer appropriate symptom management and emotional support to people diagnosed with life-threatening illness. There is also a responsibility to discuss treatment options openly with people requiring care, so that they are not led into agreeing to futile treatments when palliative care is the more compassionate and appropriate approach.

In resource-poor settings, the scope of palliative care is expanded to include the provision of social and legal support that will also assist with poverty alleviation, food security and, where appropriate, planning for the future care of potential orphans. Social and legal support can also be important in more affluent settings, but these are often sourced by the family themselves or by other support structures which are often lacking in the resource-poor setting.
Local culture and customs can influence the palliative care delivery in different settings. The carers should be aware of these so that they do not cause undue distress to the persons receiving care and their families.

Elements of palliative care

Palliative care is a comprehensive response, ideally provided by an interdisciplinary team comprising medical and nursing professionals, counseling professionals, lay personnel and volunteers, with the breakdown of responsibilities as follows:

Physical:

- Assessment (including investigation) and management of symptoms
- Clinical treatment activities
- Appropriate referral to other clinics/hospitals as may be required

Psychological:

- Emotional support
- Assessment of psychosocial needs
- Counseling – individual, family, bereavement support
- Appropriate referral to other services as may be required

Social:

- Identification of financial needs
- Poverty alleviation
- Food security
- Identification and planning care for orphans and vulnerable children
- Appropriate referral to other services as may be required

Legal:

- Identification of legal requirements
- Identification of human rights issues
- Referral to appropriate legal services

Spiritual

- Spiritual assessment
- Appropriate spiritual care
- Referral to spiritual carer according to patient's needs

The WHO definition

The WPCA recommends the following explanations of the WHO definition as applicable to all life-threatening illnesses and in all geopolitical and economic settings *(Explanatory comments are italicized)*:

<u>WHO Definition of Palliative Care</u>

Palliative Care is an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering, the early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative Care:

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process*;*

- Intends neither to hasten nor to *unduly* postpone death;
- Integrates the *social,* psychological and spiritual aspects of care *as needed and desired by patients and families;*
- Offers a support system to:
  --enable patients to access and adhere to optimal clinical care;
  --address social and legal problems and, in particular, to reduce the impact of poverty on patients and their family members, including children;
  --help patients to live as actively as possible until death;
  --help the family to cope during the patient's illnesses and in their bereavement;
- Uses a team approach *to comprehensively* address the needs of patients and their families, including bereavement counseling, where indicated;
- Will enhance the quality of life *of patients and their families*; and will also positively influence the course of illness;
- Is applicable early in the course of illness in conjunction with disease-modifying therapies implemented to prolong life, such as chemotherapy and radiation therapy *for cancer patients and antiretroviral therapy for HIV/AIDS patients*; and includes those investigations needed to better understand and treat distressing clinical complications.

Recommendations for all governments:

1) To adopt the WHO definition of palliative care

2) To integrate palliative care into their country's health care system

This will enhance the accessibility and affordability of palliative care to those people in need of this service. The essential steps to integration of palliative care into the formal health care sector include:

i) the development of a palliative care country strategy, documenting policies, procedures and standards for delivery of palliative care and recognition of palliative care specialization;
ii) education of healthcare workers in palliative care and support of these workers to transfer learned palliative care skills into their work settings;
iii) a review of the Essential Medicines List to ensure the availability of essential palliative care medication.

4) Government should be responsible for ensuring that palliative care is provided and, wherever possible, should be working in collaboration with the NGO sector in the delivery of palliative care.

Hospices and palliative care services are often provided in the non-governmental sector, relieving the formal health care sector of a significant burden of care. Hospices and home-based care organizations, providing palliative care, facilitate early identification, assessment and treatment of distressing symptoms as there is frequent contact with patients and a strong patient and family-centered approach that encourages early reporting and prompt management of problems.

Conclusion

The WHO definition is a description of compassionate, comprehensive palliative care that can be provided in any geopolitical, cultural and economic setting. The key to delivery of palliative care is

the training of healthcare workers in the principles and practice of palliative care. These principles are fully described in the WHO definition of palliative care.

---

[1] World Health Organization. WHO Definition of Palliative Care. Available from: http://www.who.int/cancer/palliative/definition/en/. Accessed June 4, 2009.
[2] Sepulveda C, Marlin A, Yoshida T, Ullrich A. Palliative Care – the World Health Organisation's Global Perspective. Journal of Pain and Symptom Management 2002; 24 (2): 91-96.
[3] Doyle D, Hanks G, MacDonald N. Introduction. In Doyle D, Hanks G, MacDonald N. (Eds) The Oxford Textbook of Palliative Medicine 2nd Ed, Oxford University Press, Oxford: 2003.
[4] Fainsinger RL, Brennis C, Fassbender K. Edmonton, Canada: A Regional Model of Palliative Care Development. Journal of Pain and Symptom Management. 2007: 33 (5): 634-639.
[5] Defilippi KM, Cameron S Promoting the Integration of Quality Palliative Care – The South African Mentorship Model. Journal of Pain and Symptom Management. 2007; 33 (5): 552-557.
[6] Kumar SK. Kerala, India: A regional Community-Based Palliative Care Model. Journal of Pain and Symptom Management. 2007; 33 (5): 623-627.
[7] Krakauer E. Just Palliative Care: Responding Responsibly to the Suffering of the Poor. Journal of Pain and Symptom Management. 2008: 36 (5): 505-512.