CAPC Boot Camp: Designing Community Palliative Care

Palliative Care Definitions

There are many definitions of palliative care created by various organizations to serve their purpose and patient population. The common elements include: care of patients with serious illness, team based interdisciplinary care, patient centered and family focused care and management of symptoms and problems across the physical, psychological, spiritual, social, and emotional domains. The goal is to relieve suffering and quality of life. Here are palliative care definitions that help ground community-based palliative program development.

Quick Links to Definitions:

- WHO Definition of Palliative Care for Children
- Regulatory - Center for Medicare and Medicaid Services (CMS)
- National Guidelines – National Consensus Project for Quality Palliative Care (NCP)
- Consumer Definitions - Center to Advance Palliative Care (CAPC)

I. The World Health Organization first created a definition of palliative care in 1990. It differentiated between hospice and palliative care and emphasized the initiation of palliative care at the diagnosis of cancer, and then promoted palliative care within a diagnosis of HIV. This definition has served as the foundation for all other definitions since it provides a worldwide perspective.

International - World Health Organization (WHO) Definition

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of 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 or postpone death;
→ 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 patients illness and in their own bereavement;
→ Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
→ Will enhance quality of life, and may also positively influence the course of illness;
→ Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

WHO Definition of Palliative Care for Children

Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.

- → It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- → Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- → Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- → It can be provided in tertiary care facilities, in community health centres and even in children's homes.

https://www.who.int/cancer/palliative/definition/en/

II. In the United States, hospice was defined in the Medicare Hospice Benefit. In the 2000s, the Center for Medicare and Medicaid Services defined palliative care to reflect the specialty practice of palliative care versus of the hospice benefit. This clarified reimbursement for both types of care.

Regulatory - Center for Medicare and Medicaid Services (CMS)

"Palliative care" means patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice.

- → https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/Downloads/Survey-and-Cert-Letter-12-48.pdf

- → https://www.cms.gov/Regulations-and-Guidance/Guidance/Manuals/downloads/bp102c09.pdf

III. In 2004, the National Consensus Project for Quality Palliative Care released the Clinical Practice Guidelines for Quality Palliative Care. It defined palliative care based on the WHO definition and the CMS definition. It has evolved over the four editions of the NCP.

National Guidelines – National Consensus Project for Quality Palliative Care (NCP)
Palliative care focuses on expert assessment and management of pain and other symptoms, assessment and support of caregiver needs, and coordination of care Palliative care attends to the physical, functional, psychological, practical, and spiritual consequences of a serious illness It is a person- and family-centered approach to care, providing people living with serious illness relief from the symptoms and stress of an illness Through early integration into the care plan for the seriously ill, palliative care improves quality of life for the patient and the family

Palliative care is:

- Appropriate at any stage in a serious illness, and it is beneficial when provided along with treatments of curative or life-prolonging intent
- Provided over time to patients based on their needs and not their prognosis
- Offered in all care settings and by various organizations, such as physician practices, health systems, cancer centers, dialysis units, home health agencies, hospices, and long-term care providers
- Focused on what is most important to the patient, family, and caregiver(s), assessing their goals and preferences and determining how best to achieve them
- Interdisciplinary to attend to the holistic care needs of the patient and their identified family and caregivers

https://www.nationalcoalitionhpc.org/ncp/

IV. In 2011, CAPC did market research to develop a definition of palliative care based on the understanding of the public and of physicians.

Consumer Definitions - Center to Advance Palliative Care (CAPC)
Palliative care is specialized health care for people living with a serious illness. This type of care is focused on providing relief from the symptoms and stress of an illness, and it is based on need, not prognosis. The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a specially trained team of physicians, nurses, and other specialists who work together with a patient’s other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness, and it can be provided along with curative treatment.

https://www.capc.org/about/palliative-care/

All websites accessed August 15, 2019.