PALLIATIVE CARE

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OBJECTIVES

Understand the principles of palliative care
Establishing goals of care
Common physical and psychological symptoms at end-of-life and a palliative care approach to address them
Recognizing end of life and provide the necessary support for patients, families and staff
Spiritual and cultural considerations
PATIENT CARE DELIVERY

Curative care:
• Efforts to cure an illness and the prolonging of life.

Palliative care:
• Comfort and quality of life that may be provided in conjunction with disease specific treatments. Life expectancy > 6 months

Hospice care:
• Focuses on comfort and quality of life when a cure is not possible and life expectancy < 6 months
Chronic Disease Burden

- Approximately 90 million Americans are living with serious illness, and this number is expected to more than double over the next 25 years with the aging of the baby boomers.
- Approximately 6,000,000 people in the United States could benefit from palliative care.
- Approximately 68% of Medicare costs are related to people with four or more chronic conditions—the typical palliative care patient. If palliative care were fully penetrated into the nation’s hospitals, total savings could amount to $6 billion per year.
WHAT IS PALLIATIVE CARE

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Typically administered in hospital or another care facility, i.e. a nursing home.

Meets both the patient’s psychological and spiritual care needs. Regards dying as a normal part of life.

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Focuses on relieving pain, reducing illness-related complications, and enhancing quality of life. Palliative care may be combined with life-prolonging treatments such as chemotherapy and radiation.

Provide support for the patient’s family.

Encourage and help the patient to live as active a life as possible until death.

Addresses the needs of patients and families through a team-based approach that includes counseling.

Likely covered by your regular medical insurance. Be aware, though, that you will be billed separately for individual items/services (similar to hospital and doctor visits). For outpatient care, expect separate billing for prescriptions, which are only covered as your regular insurance provides. For inpatient care, prescriptions may be covered. Contact your insurer, doctor, or hospital to learn more.

Appropriate for patients in any stage of illness, terminal or not.
WHAT IS PALLIATIVE CARE?

- Medical care that enhances comfort and improves the quality of an individual’s life who is facing a serious or chronic illness but the person does not qualify for hospice care.
- Palliative care is appropriate at any age and at any stage in a serious illness, and it can be provided together with curative treatment.
- The goal of care and expected outcome is relief from distressing symptoms, alleviating pain, and/or enhancing the quality of life.
What is Palliative Care?

The World Health Organization’s description:

Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.
Palliative care is a crucial part of integrated, people-centred health services, at all levels of care: it aims to relieve suffering, whether its cause is cancer, major organ failure, drug-resistant tuberculosis, end-stage chronic illness, extreme birth prematurity or extreme frailty of old age.
WHO Definition of Palliative Care

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;
WHO Definition of Palliative Care (cont.)

- Offers a support system to help the family cope during the patient's illness and in their own bereavement;
- Uses a team approach to address the needs of patients and their families, including bereavement counseling, 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 Benefits from Palliative Care?

Patients
Family
Staff
The History of Palliative Care

- Started as a hospice movement in the 19th century, religious orders created hospices that provided care for the sick and dying in London and Ireland.
- In recent years, Palliative care has gained momentum and attention from various stakeholders in healthcare, with positive impact.
- Began as a volunteer-led movement in the United states and has developed into a vital part of the health care system.
- The first US hospital-based palliative care programs began in the late 1980s at a few establishments including the Cleveland Clinic and Medical College of Wisconsin.
Palliative vs. Hospice Care

- Distinction between these two terms is made in the United States

- Other countries do not make such a distinction

- Hospice is a “type” of palliative care for those who are at the end of their lives.
Palliative care can be provided from the time of diagnosis of chronic or serious illness.
Palliative care can be given simultaneously with curative treatment.
Both services essentially have same philosophy of reducing the severity of the symptoms of an illness/sickness or old age.
Palliative vs. Hospice Care

Palliative care is aimed at anyone who has been diagnosed with a life-threatening illness.

Hospice care is mostly aimed at patients who have been diagnosed with a terminal illness.

Palliative care helps maintain quality of life and reduce illness symptoms – and recent findings suggest that cancer patients who receive palliative care alongside standard treatments can live longer.

Hospice care is aimed at providing patients with a dignified, pain-free death – in the U.S., hospice care is mostly meant to be administered inside the patient’s home, while in Russia, the concept of hospice care is just beginning to gain ground.

Source: The Mayo Clinic (mayoclinic.com) and OncologyNurseAdvisor.com
Who receives Palliative Care?

Individuals struggling with several different chronic and progressive diseases

Illnesses most commonly treated by palliative care are heart disease, cancer, stroke, diabetes, renal disease, Parkinson’s and Alzheimer’s disease.
Who Provides Palliative Care?

Interdisciplinary group of professionals
- Doctors
- Nurses
- Social workers
- Massage therapists
- Pharmacists
- Nutritionists
Palliative care Interdisciplinary team
Approaches to Palliative Care

- Individualized care is stressed.
- Not a “one size fits all approach”
- Care is tailored to help the specific needs of the patient
- Since palliative care is utilized to help with different diseases, the care provided must be individualized to address that individual’s symptoms.
What does Palliative Care Provide to the Patient?

- Helps patients gain the strength and peace of mind to carry on with daily life
- Aid the ability to tolerate medical treatments
- Helps patients to better understand their choices for care
What Does Palliative Care Provide for the Patient’s Family?

- Helps families understand the diseases/illnesses and patient care options
- Improves everyday quality of life for the patient - reducing the emotional burden on loved ones
- Provides valuable support system
Developing a Palliative Plan of Care

Members of interdisciplinary team address the following with the patients and their families:

- Goals of care
- Physical symptoms
- Psychological symptoms
- Spiritual needs
- Family needs and concerns
- Pharmacological and non-pharmacological treatment options
Goals of Care

Interdisciplinary team should:
Hold family meeting with interdisciplinary care team
  Clarify that palliative care does not mean withdrawing care, but assessing and tailoring care for the patient’s condition and symptoms
Complete advance directives
Identify and alleviate any emotional burdens of the family as may be overwhelmed
Discuss time frame to meet the set goals of care
Revisit plan frequently with team, including family
Approaches to Palliative Care

A palliative care team helps the patient and family through:

- Frequent and timely communication with the doctors
- Provide appropriate management of pain and other symptoms
- Guidance with difficult and sometimes complex treatment choices
- Help navigating the complex healthcare system
- Provide emotional and spiritual support for the patient and their family
Palliative Care Is Effective

- Successful palliative care teams require empathetic and dedicated individuals who are willing to collaborate with one another.
- Recent studies show that patients who receive palliative care report improvement in:
  - Pain and other distressing symptoms, such as nausea or shortness of breath
  - Communication with their doctors and family members
  - Emotional and psychological state
Settings for Palliative Care

- Hospital/ Inpatient

- Outpatient practice:
  - Home care
  - Nursing Home
  - CBRF/ Community Based Residential Facilities
  - Assisted Living facilities
  - Hospice situations
Symptoms at End-of-Life

- Pain
  - Common, complex issue
- Respiratory Symptoms
  - Shortness of breath, coughing, wheezing
- Gastrointestinal Symptoms
  - Nausea, constipation
- Psychological Symptoms
  - Depression, delirium, anxiety
Interventions

- Scheduled versus PRN medications, especially for pain
- Oxygen, nebulizers/ inhalers, diuretics, cough relief medications
- Anti-emetics, Laxatives, Anti-diarrheal, bowel regimen
- Anti-depressants, anxiolytics
- Sleep aids
- Non-pharmacological therapies
Addressing Spiritual Needs

- should be addressed at the beginning and not wait until the last minute!
- Offer options such as background religious music, electronic and non-electronic options for religious/spiritual wellbeing
- Arrange visit from their priest/pastor/religious leader
- Encourage/facilitate religious or traditional activities/rituals
- Help facilitate discussion regarding and arrangements for fumeral
Each of us is part of one or more cultures depending on our heritage

Race, ethnicity, religion, lifestyle contribute to culture

Culture
  - Is manifested through values, customs, behaviors & beliefs
  - Affects decision-making and views re: death and dying and palliative care
Preserving Personhood and Dignity

- Attention to personal hygiene - bathing, grooming, bowel and bladder care
- Oral hygiene/care
- Odor control
- Comfortable clothing and bedding
- If not at home, then try to promote home-like environment with familiar/personal items such as pictures, bedding, etc
Final Hours/ End of life

- Common symptoms can be distressing to patient and family
  - Pain, breathing difficulty, delirium
- Provide appropriate symptom control
- Limit/withhold food and fluid intake if necessary
- Maintain personhood/ dignity
  - Talk to the individual and family frequently
Supporting the Family

- Address their questions
- Provide frequent updates
- Provide relevant information
- Offer suggestions to support/care for the patient
- Pay attention to their comfort
  - food, drinks, sitting/sleeping arrangements, tissues
- Offer interdisciplinary support
  - enlist help from Social workers, Chaplain/religious persons, counselors.
Data suggest there is growth in palliative care programs throughout the nation's hospitals, larger hospitals, academic medical centers, not-for-profit hospitals, and VA hospitals are significantly more likely to develop a program compared to other hospitals.
The 2015 Report Card shows a continued increase in the number of hospital palliative care teams in the United States: 67 percent of U.S. hospitals with fifty or more beds report palliative care teams, up from 63 percent in 2011 and 53 percent in 2008. The number of states with A grades (defined as more than 80 percent of the state’s hospitals reporting a palliative care team) also increased, from 3 percent in 2008 to 17 percent in 2015.
For the first time no state has a grade of F (defined as less than 20 percent of a state’s hospitals reporting a palliative care program). Important gaps still remain.

Wisconsin is listed as grade A 87.2%

One-third of U.S. hospitals with fifty or more beds report no palliative care services, and one-third of the states received a grade of C or D.

The overall grade for the United States in 2015 was a B, unchanged from 2011.
Where to find Palliative Care?

- In most cases, palliative care is initiated in the hospital.
- The process begins when doctors in the hospital or ambulatory setting refer individuals to the palliative care team.
- The Palliative Care Provider Directory of Hospitals at www.getpalliativecare.org can locate hospitals which provide palliative care.
Cost of Palliative Care

Most insurance plans, including Medicare and Medicaid, cover all or part of palliative care.