Palliative Care and End of Life

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- March 23rd 2022
Objectives

Define Palliative care

Define End of Life Care

Define Hospice

Goals of Palliative Care
Palliative Care

Medical care delivered by a healthcare trained specialist that focuses primarily on symptom management to improve the patient’s (with any serious, chronic, or life-threatening illnesses) quality of life.

(Murray, 2017)
Goal of Palliative Care

To improve the quality of life for individuals who are suffering from severe diseases.

Palliative care offers a diverse array of assistance and care to the patient.
**Palliative Care**

<table>
<thead>
<tr>
<th>Provides relief from pain and other distressing symptoms</th>
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<tr>
<td>Affirms life and regards dying as a normal process</td>
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<td>Intends neither to hasten or postpone death</td>
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<td>Integrates the psychological and spiritual aspects of patient care</td>
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<td>Offers a support system to help patients live as actively as possible until death</td>
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Began as a hospice movement in the 19th century.

The first US hospital-based palliative care programs began in the late 1980s at a few establishments including the Cleveland Clinic.

Began as a volunteer-led movement in the United States and has developed into a vital part of the health care system.

Since the inception there has been a dramatic increase in hospital-based palliative care programs, now numbering more than 1400.
Palliative Care Team

- Composed of a physician, and/or nurse practitioner, chaplain, social worker and nurse, to provide holistic care to patients

- The palliative care team’s focus is on addressing physical, psychosocial, spiritual, and existential pain (Ferrell et. al, 2018)
Palliative Care Team

Patient and Family

Nurses
Volunteers
Physicians
Therapists
Spiritual Counselors
Home Health Aides
Pharmacists
Social Workers
As life expectancy increases and diseases become more chronic in nature, early introduction of palliative care in many patients leads to longer life and better quality of life. Palliative care has risen by 178% from 2000 to 2016 (CAPC, 2018). Dominant illnesses for which palliative care will be needed are dementia and cancer (Etkind et. al, 2017).
Effects of Early Integrated Palliative Care in Patients With Lung and GI Cancer: A Randomized Clinical Trial

• **Methods:**
  – Newly diagnosed incurable GI and Lung Cancers within 8 weeks of diagnosis
  – Sample size = 350 patients
  – Done at Massachusetts General hospital
  – Non blinded, randomized trial
  – Study conducted from May 2011 to July 2015

Effects of Early Integrated Palliative Care in Patients With Lung and GI Cancer: A Randomized Clinical Trial

• Methods:
  – Randomly assigned to two Groups:
    • Group with early integrated Palliative Care (PC) and oncology care (n = 175)
    • Usual Oncology care (n = 175)

Effects of Early Integrated Palliative Care in Patients With Lung and GI Cancer: A Randomized Clinical Trial

• Methods:
  – Patients assigned to the intervention met with a PC clinician at least once per month until death
  – Patients who received usual care could consult a PC clinician upon request
  – Excluded patients who already had palliative care
  – Utilized the National Consensus Project for quality Palliative Care guidelines
  – Follow up assessments at 12 weeks and 24 weeks

(Temel et. al, 2017)
Effects of Early Integrated Palliative Care in Patients With Lung and GI Cancer: A Randomized Clinical Trial

• **Tools:**
  - Functional Assessment of Cancer Therapy General Scale (FACT-G) scale used to measure quality of life
  - Patient health Questionnaire used to measure mood and anxiety
  - Hospital Anxiety and Depression Scale
  - Prognosis and Treatment Perceptions Questionnaire measured patient understanding of their disease and communication with oncologist

(Temel et. al, 2017)
Results

• Primary end point was change in quality of life (QOL) from baseline to week 12

• Secondary end points included:-
  – Change in QOL from baseline to week 24
  – Change in depression
  – Differences in end-of-life communication

(Temel et. al, 2017)
Results

• Intervention patients showed
  – Greater improvement in QOL from baseline to week 24
  – Lower rates of depression at week 24

• Intervention patients with lung cancer had improvement in QOL and depression at 12 & 24 weeks

• Usual care patients with lung cancer had poor QOL

• Patients with GI cancers in both study groups had improved QOL and mood by week 12.

• Intervention patients were more likely to discuss end of life wishes with their oncologist

(Temel et al, 2017)
• Patients with newly diagnosed incurable cancers had
  – Improved QOL and mood with early integrated PC
  – Early integrated PC may be most effective if targeted to the specific needs of each patient population.

(Temel et. al, 2017)
Two key areas of focus are

- Early access to palliative care despite patient setting, diagnosis, age or prognosis.
- Empowering clinicians to introduce palliative care early in the disease trajectory
Approaches to Palliative Care

- Care is tailored to help the specific needs of the patient
- Not a “one size fits all”
- Vital for comfort to reduce patients’ distress
- Patients with good pain and symptom management tend to tolerate treatment better and have better quality of life
Emotional and spiritual distress are extremely important as they can affect quality of life and treatment adherence as well.

Psychosocial support
What does Palliative Care Provide to the Patient?

- Helps patients gain the strength and peace of mind to carry on with daily life
- Aids the ability to tolerate medical treatments
- Helps patients to better understand their choices for care
Five Themes of Care

- Five themes include
  - Comprehensive assessment
  - Family/caregiver assessment
  - Support and education
  - Care coordination during transitions
  - Culturally inclusive care

(Ferrell et al., 2018)
Comprehensive assessment

• Should include physical, psychosocial, spiritual and cultural aspects of care

• Team should be interdisciplinary in nature with each focusing on their specialized area to provide holistic care

• Collaborate with patient and caregivers to develop a treatment plan focused on patients’ goals, maximizing functionality and optimizing quality of life

• Continuous assess and reassess of the patients' goals are needed as the course of the disease changes

(Ferrell et al., 2018)
Caregiver

Care also focuses on the caregiver and family

Majority of patient care is done by caregivers

Caregivers can experience caregiver burnout if not educated appropriately (Bakitas et al, 2015)

Caregiver burnout encompasses emotional, psychological and physical stressors such as fatigue, stress, anxiety, and depression. Caregivers who suffer from these tend to have high mortality rates (Bakitas et al, 2015).

Patients and families who have early onset palliative care, have a better knowledge of symptom management at home and tend to feel more supported in caring for their loved ones (Gomes, 2015)
Advance care planning

- Process by which patients can delineate their wishes and preferences regarding future medical care

- Directives are only implemented when a patient loses the ability of making medical decisions on their own

- Legal documents directing medical care

- As the medical course of the patient changes, advance care planning should be readdressed with the continued focus remaining on honoring patients’ preferences

- Can be revoked or changed at any time by the patient

(Sudore et al, 207)
Code Status

- Types of code statuses
  - Full Code
  - DNR– No Intubation/No ACLS (No Code)
  - DNR Comfort Measures Only (CMO)

Patients can continue treatment and still be a DNR
Palliative Care vs Hospice

• Palliative care differs from hospice in that it does not solely focus on end of life

• Initiated at any stage of the disease and at any time during the disease trajectory

• Can be used in conjunction with curative treatment

• Focuses on a wide spectrum of disease

(Kaplan, 2010)
Hospice

• Palliative Care for patients with life-limiting illness

• Began in the United States in 1965 when Dame Cicely Saunders came to speak at Yale about the care of dying (National Hospice and Palliative Care Organization, 2016)

• Founder, Florence Wald, Hospice of Connecticut, 1974 (National Hospice and Palliative Care Organization, 2016)

• Model of care for people who are facing life-limiting illness (National Hospice and Palliative Care Organization, 2018)

• Encompasses expert medical care, pain & symptom management, and emotional and spiritual support which is personalized to the pt’s wishes and goals & focuses on quality of life and living life to the fullest
Hospice Care

• Usually provided in the home but can be provided in other settings

• Care is provided by interdisciplinary team and the family/significant other(s) who serve as the primary caregiver (National Hospice and Palliative Organization, 2018)

• Services address the physical, psychosocial, and spiritual needs of the pt and their family caregivers

• Upon election of hospice care, pts forgoes all treatments with curative intent & focus on comfort

(Kaplan, 2010)
Our Culture and Reaction to Dying

- Prolonging life by using medical technology has increased with more people dying in the hospital.

- Oldest and frailest citizens live in nursing homes and assisted living facilities, shielding society from the realities of aging or death.

- Death denying described in 1970s as identified by Kubler-Ross.

(Tofthagen et al., 2019)
Our Culture and Reaction to Dying

Some hospices have dropped the word hospice from their name to make the concept of hospice more palatable.

Added palliative care services.

Changed name from palliative care to supportive care.
Perceptions of Hospice

- Last resort
- A place to die
- A method to hasten death
- Denies access to life saving treatments
- “Giving up”

(National Hospice and Palliative Care Organization, n.d.)
Policy and Payment

- Covered by Medicare A, Medicaid, Veteran’s Health Administration and most private insurance.

- Medicare is the largest payer for hospice services through the Hospice Medicare Benefit (Institute of Medicine, 2015).

- Medicare pays a set daily rate.

- To be eligible for the hospice Medicare benefit, two physicians must attest that the individual has a prognosis of six months or less.

- Hospice Medicare Benefit has four levels of care to meet patients’ clinical needs: routine home care, general inpatient care, and inpatient respite care.

- Most hospices meet numerous regulatory standards to provide quality care and eliminate fraud.

(National Hospice and Palliative Care Organization, 2018)
Current Trends in Hospice Care in the United States

• Hospice utilization will continue to grow

• As we grow older, our Medicare population grows

• May be influenced by the increase in the number of for-profit hospices

• Trend towards the use of experiential and alternative therapies

• Emerging trend of telemedicine in hospice care

• Regulatory issues with scrutiny of hospice compliance

(Baxter, 2018)
Care at End of Life

Observable Physical Changes as Death Approaches

Common Symptoms in Cancer at End of Life and Their Management

Psychosocial Dimensions of Care

(Baxter, 2018)
Stages of Death and Dying

• Denial – Refuses to believe
• Anger- When no longer able to deny
• Bargaining- Accepts death, but wants more time
• Depression- Determines death will come soon
• Acceptance- Understand and accepts situation

Kubler-Ross 1970’s
Stage I
Early Phase of Dying

• Few days to several weeks
  – Terminal Anorexia
  – Dysphagia
  – Early satiety
  – Fatigue/Drowsiness
  – Weakness

(Moses, 2014)
Stage II
Middle Phase of Dying

- Last few hours to several days
  - Changes in BP and HR
  - Cool Extremities and Cyanosis
  - Oliguria (< 500 mL)
  - Bedbound
  - Severe Dysphagia
  - Cheyne Stokes Respirations
  - Death Rattle/Airway Congestion
  - Near Comatose
  - Terminal Delirium
  - Respirations by Mandibular Movement

(Moses, 2014)
Stage III
Last Stage of Dying

- **Hours**
  - Increasing Cheyne Stokes with longer periods of apnea & rate decreasing
  - Chest congestion and throat rattling (Death rattle)
  - Mottling in extremities (blotchy, red-purplish marbling of the skin)
  - Neck Hyperextension with mouth breathing
  - Lack of Rectal Tone
  - Loss of Radial Pulses
  - Restlessness/Agitation

(Moses, 2014)
Imminent Death

- Expected within hours
- Death Rattle
- Cyanosis/Mottling
- Long shallow, irregular, apneic pauses
- Loss of Both Radial Pulses
Management

- Provide support
- Promote healthy grieving
- Ensure that the Family/Caregiver understands the signs of dying
- Consider spiritual care and social work consults
- Support cultural practices
- Ensure deactivation of implanted devices
- Ensure that caregivers understand and will honor advance directives of patient
- Offer anticipatory bereavement support

(NCCN, 2019)
Common Symptoms in Cancer at End of Life

• Pain
  – Assess
  – Manage with Opioids which may include SL, IV, or SQ
  – Opioid doses should not be reduced for decreased bp, respiration rate, or level of consciousness
  – Opioids should be titrated aggressively to provide optimal comfort
Terminal Secretions

- Reduce parenteral and enteral fluids
- Reposition the patient
- Avoid deep suctioning
- Scopolamine 1.5 mg patch Q 72 h
- Atropine ophthalmic drops 1% 1-2 gtts SL q 4h PRN
- Glycopyrrolate 0.2-0.4 mg IV or SQ q 4h PRN
- Hyoscyamine 0.125 mg SL q 4h PRN

(NCCN, 2019)
Dyspnea

- Most common symptom with advanced lung cancer
- Fan directed at the face
- Cooler temperatures
- Supplemental oxygen
- Treatment with:
  - Benzodiazepines
    - Lorazepam 0.25-1 mg PO/SL/IV q 4 h PRN
  - Opioids
    - Morphine 2.5-10 mg SL/PO q 2 h PRN or 1-3 mg IV q 2 h PRN

(NCCN, 2019)
Terminal Delirium

- Hypoactive verses hyperactive

- Benzodiazepines should not be used as initial treatment of delirium

- Benzodiazepines may be effective in the setting of persistent agitation

- Haloperidol is 1st line agent for managing symptoms of delirium

- Provide family/caregiver support and education

- Decrease doses of medications dependent upon hepatic or renal function

- Consider that under-or over treatment of pain may exacerbate delirium

(NCCN, 2019)
Terminal Delirium

- Mild to moderate delirium
  - Haloperidol, 0.5-2 mg PO BID/TID
  - Alternatives: Risperidone 0.5-1 mg PO BID; olanzapine, 5-20 mg PO daily; quetiapine fumarate, 25-200 mg PO/SL BID

- Severe delirium (agitation)
  - Haloperidol, 0.5-2 mg IV every 1 to 4h PRN
  - Alternatives: olanzapine, 2.5-7.5 mg PO/SL every 2-4h PRN (maximum = 30 mg/d); chlorpromazine, 25-100 mg PO/PR/IV q 4h PRN

- Palliative sedation
  - Midazolam, continuous infusion
  - Propofol, continuous infusion

(NCCN, 2019)
Psychosocial Dimensions of Care

- Functional Losses
  - Unable to work / handle personal affairs
  - Loss of sense of enjoyment
  - Limited social contacts

(NCCN, 2019)
Psychosocial Dimensions of Care

• Patient Reactions
  – Self Pity
  – Fear
  – Anger
  – Worry over not completing tasks or reaching life goals
  – Development of apathy, withdrawal, and depression

(Kuebler et al, 2005)
Psychosocial Dimensions of Care

• Family Relationships
  – Burdened by concern for family
  – What will happen to loved ones
  – Spouses being able to cope with finances
  – End of shared promises and experiences

(Kuebler et al, 2005)
Psychosocial Dimensions of Care

- Personal Dignity

  Treating patient as person, not disease

(Kuebler et al, 2005)
Myth vs Fact

Palliative care is just for individuals with cancer

(Kuebler et al, 2005)
Myth vs Fact

Only people who are “very ill or dying” can complete advanced directives
Myth vs Fact

• Discussing palliative care with individuals and caregivers can “be discouraging and diminish hope”
Myth vs Fact

Palliative care can only be utilized for pain and other physical symptoms

(Kuebler et al, 2005)
 Pearls

- Be Honest
- Be Empathetic
- Be compassionate
THANK YOU
Questions?
References


