UNDERSTANDING HOSPICE AND PALLIATIVE CARE

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Palliative Care - Ethical and Psychological Support
OBJECTIVES:
1. Discuss the state-of-the-art of palliative medicine and national guidelines for quality palliative care
2. Provide three major domains of Quality Palliative Care
3. Delineate developmental ethical imperatives in caring for older adults with life-altering, life-threatening and life-limiting disease
4. Explore ways to infuse hope and total healing

Single Cancer Stem Cell

Cancer Stem Cells
- Cancer cells are often perceived as all having the same potential to proliferate and expand the disease, but in many types of cancer only a small subset of tumor cells have that power.
- The tumor-generating cells share key traits with stem cells (pluripotential), including an unlimited life span and the ability to generate diverse range of other cell types and are therefore considered cancer stem cells.
- These malignant progenitors are believed to spring from regulatory failures in damaged stem cells or their immediate offspring.
- Cancer treatments must target cancer stem cells in order to eradicate the cancer.

Hospice and Palliative Medicine
Historical Perspective: Symbolic Thanatology
- Science has provided us with a very detailed process of how humans are created, even cloned, but little is known about how we die. French historian, Philippe Aries, suggested that to study the evolution of care in a short period of time is to attribute effects to the wrong causes, since fundamental changes are slow to take effect. Nonetheless, the process of dying remains a relative mystery even in today's advanced technology.

Hospice and Palliative Medicine
- A thousand years ago, monks from the Abbey of Cluny in France provided us with prayers, music (chants), spiritual teachings to the sacred art of dying. Harpist, Therese Schroeder-Schecher has refined music thanatology as a very important therapeutic tool in addressing major domains of suffering, thus providing patients with a peaceful and comfortable journey.
- Groves R. The Sacred Art of Dying. St Anthony Messenger Press, Cincinnati, Ohio
Hospice and Palliative Medicine

In the early years of hospice in America, hospice services were primarily provided to patients with cancer. Many hospices in America still just provide care for patients with a terminal cancer.

One reason for this practice was due to the influence by St. Christopher’s Hospice, the prototype of the hospice movement worldwide started by Dame Cicely Saunders, Foundress of the Hospice Movement.

A second reason could have been because in the care of cancer patients there is usually a very distinct disease trajectory; a stochastic point when therapeutic interventions are no longer a realistic goal and quality of life becomes the focus for patients and their family.

Hospice and Palliative Medicine

- End of life care is focused on relieving the four dimensions of suffering
  - Physical
  - Psychological
  - Social
  - Spiritual
  - Addressing the fragmentation of personhood - Eric Cassell, MD
  - Total Pain - Cicely Saunders
  - The challenge of meaning - Ira Byock
  - AMA: The EPEC Project

Hospice and Palliative Medicine

- Concepts of Hospice:
  - Comfort vs. Cure
  - Symptom Management
  - Home environment
  - Patient and Family as a Unit of Care
  - Interdisciplinary Team
  - Addressing ethical issues
  - Strong emphasis on social, psychological and spiritual issues
  - Grief support and bereavement

Hospice and Palliative Medicine

- Medicare Hospice Benefit established under the Tax Equity and Fiscal Responsibility Act (TEFRA) in 1982, effective and funded in 1983.
- Balance Budget Act (BBA) 1997 changed benefit periods to:
  - Two benefit periods of 90 days
  - Unlimited 60 day resynchronization as long as patient has a terminal diagnosis

Hospice and Palliative Medicine

- Medicare Hospice Benefit and most Third Party Payors
  - Eligibility:
    - Terminal diagnosis with a prognosis of 6 months or less if illness process follows the natural course of the disease
    - Physician certifies terminality.
    - Patient, family and physician understand and elect palliative or comfort measures

Hospice and Palliative Medicine

- The Medicare program consists of two parts: Part A - Hospital Insurance and
  - Part B - Medical Insurance
- The Hospice benefit is provided under Medicare Part A. Hospice benefits are available to Medicare beneficiaries who have Medicare Part A, a terminal illness as certified by their doctor and the hospice medical director and sign the hospice election statement choosing hospice care. The Hospice Medicare Benefit only applies to the terminal diagnosis. So patients still have their regular Medicare Benefit for diseases not related to the terminal diagnosis. Most insurers and managed care companies also provide a hospice benefit.
Hospice and Palliative Medicine

- You must be entitled to Medicare Part A to receive Hospice Services
- Veteran Hospitals provide hospice and palliative care in the hospital and VA nursing home facilities
- Dually eligible veterans may elect to receive Medicare hospice services while residing in a community nursing home and state homes and have those services paid for under the Medicare hospice benefit.

Hospice and Palliative Medicine

- Levels of Care and avg. US rates based on Wage Index and Metropolitan Statistical Area (MSA).
  - Routine hospice home care
  - General Inpatient hospice care
  - Respite care
  - Continuous care

Hospice and Palliative Medicine

Hospice Interdisciplinary Team:
Registered Nurse and Licensed Vocational Nurse
Physician
Certified Nurse Assistant
Medical Social Worker
Chaplain
Bereavement Counselor
Volunteers
Other ancillary personnel

Palliative Care Definition

- The goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for patients and their families, regardless of the stage of the disease or the need for other therapies. Palliative care is a philosophy of care and an organized, highly structured system for delivering care. Palliative care expands traditional disease-model medical treatments to include the goals of enhancing quality of life for patient and family, optimizing function, helping with decision-making and providing opportunities for personal growth. As such, it can be delivered concurrently with life-prolonging care or as the main focus of care.

Hospice and Palliative Medicine

- Palliative care is operationalized through effective management of pain and other distressing symptoms, while incorporating psychosocial and spiritual care with consideration of patient/family needs, preferences, values, beliefs, and culture. Evaluation and treatment should be comprehensive and patient-centered with a focus on the central role of the family unit in decision making. Palliative care affirms life by supporting the patient and family's goals for the future, including their hopes for cure or life-prolongation, as well as their hopes for peace and dignity throughout the course of illness, the dying process, and death.

Hospice and Palliative Medicine

- Palliative care aims to guide and assist the patient and family in making decisions that enable them to work toward their goals during whatever time they have remaining. Comprehensive palliative care services often require the expertise of various providers to adequately assess and treat the complex needs of seriously ill patients and their families. Leadership, collaboration, coordination, and communication are key elements for effective integration of these disciplines and services (NCP 2004).
Advances in Palliative Medicine

- A Vision for Better Care at the End of Life, Last Acts - Five Principles of Palliative Care
- AMA, Institute of Ethics - Education of Physicians on End-of-Life Care (EPEC Project)
- Moyer's on Dying, PBS Series - "On our Own Terms"
- Specialties in Medicine - Milbank Memorial Fund: Core Principles for End of Life Care
- National Consensus Project: Clinical Practice Guidelines for Quality Palliative Care
- National Hospice and Palliative Care Organization
- American Academy of Hospice and Palliative Medicine

State-of-the-Art of Palliative Medicine

- Hospice and Palliative Nurses Association certification for RN, LVN, APN
- Center to Advance Palliative Care - Mount Sinai School of Medicine
- American Board of Medical Specialties - 10 Boards recognized Hospice and Palliative Medicine as a subspecialty and AOA certification in Palliative Medicine
- 41 accredited fellowships in palliative medicine
- 15 major journals devoted to palliative medicine
- Major research grants dedicated to palliative medicine.

National Consensus Project - Clinical Practice Guidelines for Quality Palliative Care

- Goals:
  - Facilitate the development and continuing improvement of clinical Palliative care programs providing care to patients and families with life-threatening and debilitating illness.
  - Establish uniformly accepted definitions of the essential elements in palliative care that promote quality, consistency, and reliability of these services.
  - Establish national goals for access to quality palliative care.
  - Foster performance measurement and quality improvement initiatives in palliative care services.
  - Foster continuity of palliative care across settings (home, residential care, hospital, hospice).

Domains of Quality Palliative Care

- Structure and Process of Care
- Physical Aspects of Care
- Psychological and Psychiatric Aspects of Care
- Social Aspects of Care
- Spiritual, Religious and Existential Aspects of Care
- Cultural Aspects of Care
- Care of the Imminently Dying Patient
- Ethical and Legal Aspects of Care.

Definitions of Pain

- Acute Pain - usually follows injury to the body and disappears when the injury heals. Often, but not always, associated with autonomic nervous system stimulation, i.e., tachycardia, hypertension, diaphoresis, mydriasis and pallor. It is rarely justified to defer analgesia until a diagnosis is made.
- Cancer Pain - may be acute, chronic or intermittent, and usually has a definable cause, i.e., tumor progression or treatment.

Patients at Risk for Pain

- Cancer
- Non-cancer illness:
  - Dementia
  - Cardiovascular disease
  - Pulmonary disease
  - Neurological disease: stroke, ALS, MS, Muscular Dystrophy, mentally impaired
  - End Stage Organ Disease: Renal, Liver
  - AIDS
  - Osteoarthritis, RA, Vertebral Compression Fx.
  - Congenital Anomalies - Trisomy's, SMA, Leukodystrophies, Sickle Cell Disease, etc.
Definitions of Pain

- Chronic Pain: Is rarely accompanied with signs of sympathetic stimulation. It is important to address all domains of suffering in treating chronic pain: physical, social, psychological, spiritual. Acute pain may be superimposed over chronic pain causing a crescendo/descending clinical picture. Lack of objective signs of chronic pain may cause the inexperienced clinician to discount the patient’s level of pain.

- Chronic pain may be accompanied by: anxiety, hostility, loneliness, depression, insomnia, anorexia, frustration, anger, and/or suicidal ideation.

Pain Assessment Tools

- Visual Analogue Scales:
  1. Descriptive Scale: 0-10, describing no pain as zero and worst pain as ten
  2. Wong-Baker Faces: 0-5, faces of no pain to severe pain
  3. Numeric scale: 0-10, Zero no pain; rating of mild pain from 1-3; moderate pain from 4-7 and severe pain from 8-10
  4. Pain Thermometer in the elderly: 0-10, zero is no pain; 1-2 is little pain; 3-4 is moderate pain; 5-6 is quite bad pain; 7-8 is very bad pain; 9-10 pain that is almost unbearable

Nonspecific Behavior Observations Suggesting Pain

- Non-Verbal Behaviors:
  - Restlessness, guarding, bracing, rubbing, fidgety, striking out, recurrent agitation
  - Vocalizations:
    - Crying, moaning, groaning, calling out, sighing, labored breathing
  - Facial Expressions:
    - Flourishing, grimacing, wincing, fearful faces, grinding of teeth
  - Others:
    - Decrease in ADL, function, appetite, sleep
    - Resisting ROM during care, abnormal gait
    - Hand grip
    - Chronic Pain Management in the Long-Term Care Setting. AMDA, Clinical Practice Guidelines, 1999, Modified by A. Parrella

Ethical Issues in Palliative Medicine

- As medical professionals we must be cognizant that our clinical clarity in treating diseases sometimes becomes absent when caring for the terminally ill; therefore, we must be willing to accept the uncertainty in the dynamic care of patients near death and consistently focus on providing comfort both physically and psycho-spiritually.

Barriers to Pain Management

- PATIENT
  - "Wimp"
  - Fear of adverse drug effects/events
  - Fear of addiction
  - Other illness or disease/pathology
  - Knowledge deficit

- CAREGIVER
  - Knowledge deficit
  - Fear of opioids
  - Legal pressure
  - Pain as a "symptom"
  - Fear of addiction
  - PRN
Chronic Pain Misconceptions in the Elderly

- Personal weakness to acknowledge pain and conversely, strength in character to bear pain.
- Chronic pain is part of aging.
- Chronic pain is a punishment for past actions.
- Chronic pain heralds a serious disease.
- Acknowledging pain will cause painful and invasive testing and loss of autonomy.
- Cognitively impaired elders have higher thresholds and cannot be assessed for pain.
- Elders in LTCF seek attention with pain symptoms and are likely to become addicted to pain medications.

- Chronic Pain Management in the Long-Term Care Setting, AMDA, Clinical Practice Guidelines. 1999.

Ethical imperatives to adequate pain management

- MORAL ISSUES:
  - Patients have a strong prima facie right to freedom from unnecessary pain.
  - Pain is dehumanizing.
  - Pain destroys autonomy. The Ethical Principal of Autonomy allows self-determination by patients.
  - Pain is humiliating.
  - In its extreme, pain destroys the "soul" itself and all will to live.


CLINICAL INDICATORS FOR HOSPICE

Weight Loss
Uncontrolled or Increased Pain
Withdrawn, Confused, Bed Bound
Profound Weakness, Fatigue
Difficulty Breathing
Oxygen Dependence
Progressive Renal Insufficiency
Progressive Edema
Frequent Infections
Frequent Hospitalizations
Decubitus Ulcers, Stage III or IV
Failure To Respond To Medical Treatment

The Wasting Syndrome of Cachexia and Fatigue

- Debility, unspecified
- Definition:
  - ICD-9 Section 16: Symptoms and Signs and Ill-defined conditions (780-799)
  - Under sub-section "ill-defined and unknown causes of morbidity and mortality (797-799) you will find code 799.3 – debility unspecified
  - This diagnosis depicts the nature of a terminal illness in the elderly who are severely or terminally debilitated and whose death is inevitable due to the progressive and cumulative failure of multiple vital organs or multi-system failure.

The Wasting Syndrome of Cachexia and Fatigue

- Adult Failure to Thrive Syndrome
- Institute of Medicine definition:
  - A syndrome late in life manifested by weight loss greater than 5% of baseline, decreased appetite, poor nutrition, and inactivity often accompanied by dehydration, depressive symptoms, impaired immune function, and low cholesterol levels.

The Wasting Syndrome of Cachexia and Fatigue

- Cachexia a serious but under-recognized consequence of many chronic diseases. Prevalence ranges 5-15% in end-stage chronic heart failure to 50-80% in advanced cancer.
- A part of the terminal course of many patients with chronic Heart Failure, kidney disease, COPD and rheumatoid arthritis.
- Annual Mortality rates
  - 10-15% - COPD
  - 20-30% - HF and kidney disease
  - 80% - Cancer

(Cachexia, Sarconeia and Musc 2014. 5: 261)

Current status of Physician Aid in Dying and of Voluntary Active Euthanasia in the U.S.

- Legal in 4 (5) states
  - Oregon, Washington by referendum
  - Montana (and New Mexico) by court ruling
  - Vermont by legislation
- Illegal or uncertain status in most other states
- Much uncertainty surrounds the "secret" practice
- "Don't ask, don't tell" approach very problematic
- Voluntary active euthanasia illegal in all U.S. states, and very likely to be prosecuted if discovered

Hope and Healing

- Hope is an expectation greater than Zero of achieving a goal
  - Robert Twycross, Pain expert and pioneer in palliative medicine.
- Hope is an orientation of the spirit, an orientation of the heart. It is not the conviction that something will turn out well, but the certainty that something makes sense, regardless of how it turns out.

The Myth Of Life

- People say that what we're all seeking is a meaning for life. I don't think that's what we're really seeking. I think that what we're seeking is an experience of being alive, so that our life experiences on the purely physical plane will have resonance within our own innermost being and reality, so that we actually feel the rapture of being alive."
Healing Assertions:

- We are people who are intrinsically spiritual.
- We are people who need to attend to the spiritual dimensions of life.
- We are people in need of reflection and spiritual nourishment.

- Peralta, A. Comparing NDE vs. NPOC, Clinical Team Conference, 2009.

Psycho-Spiritual Moratorium

- This phase of Psycho-Spiritual Moratorium is a time-out. This time out allows the evolution of a transpersonal template of transcendence based on current and nostalgic experiences. It is the formation of a spiritual dimension of the vita viscera humana in its final phase of development - a natural self-effacing way of approaching an unseen order.

- Peralta, A. Comparing NDE vs. NPOC, Clinical Team Conference, 2009.

Psycho-Spiritual Moratorium

- Our teachers, in the formation of this spiritual dimension, have been prophets, shamans and friends. Mahatma Gandhi, Martin Luther King, Mother Teresa, Morrie Schwartz and St. Jose Maria Escriva (founder of Opus Dei) exemplified this spiritual dimension. They believed in the sanctification of daily life and pure love in relationships. The opportunity on a daily basis to make everyone you meet successful. It was the embodiment of these human relationships that gave them the buoyancy to transcend to the unknown.


Healing

- Is a state of mind when our body, mind and spirit are in harmony with our most inner self. We call this an epiphany - the oneness of self. Where deep-touchings and oneness flourish. Where forgiveness can be extended and received, material things are put in order, broken relationships can be mended and absolute love exists.

- It is how we philosophically orient ourselves in nostalgic and practical ways to an unseen order. Modified by Alexander Peralta MD

- Jean Green, Theologian, paraphrased from Varieties of Religious Experience by William James

Hospice and Palliative Medicine

Major Issues for patients with acute and chronic advanced illnesses:

- Pain – Symptom Management
- Loneliness – Religious and Existential Issues
- Loss of Control – Ethical Issues (our final disengagement)


The Hospice Heart

- Hospice is intensive human caring. It is the integration of the bio-technical primary worldview of treatment of diseases with the psychosocial and spiritual secondary worldview of symptom management when cure is no longer an option. As physicians, we believe that the privilege to learn from patients as they write their final chapters is where the art and science of medicine truly lives, Alexander Peralta, MD

- It is the time when good-byes can be said, material things can be put in order, broken relationships mended, forgiveness extended or received, and when love, which may never have been expressed before, can finally be expressed. Josefin B. Magno, MD