

The Art of Palliative Care: Stories From the Heart

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Cause of Death/Demographic and Social Trends

	Early 1900s	Current
Medicine's Focus	Comfort	Cure
Cause of Death	Infectious Diseases/ Communicable Diseases	Chronic Illnesses
Death rate	1720 per 100,000 (1900)	807 per 100,000 (2013)
Average Life Expectancy	50	80-84
Site of Death	Home	Institutions
Caregiver	Family	Strangers/ Health Care Providers
Disease/Dying Trajectory	Relatively Short	Prolonged

CDC, 2014

Palliative Care in America

- Late 1800's
 - Death common
 - Families often cared for loved ones with chronic and terminal illness
 - Death and dying was a normal part of life
- Early to mid 1900's
 - World War II
 - Discovery of Penicillin
 - Life expectancy increased
- Today
 - Focus from comfort to cure

Leading Chronic Illnesses

- Heart Disease
- Cancer
- Chronic Lower Respiratory Diseases
- Cerebrovascular Disease
- Alzheimer's Disease
- Diabetes
- ESRD

Cardiovascular Mortality Statistics

- Leading cause of death in the United States
 - Accounts for 25% of all deaths
- More than 7,500 Americans die each day of CVD
- Many patients experience a slow, progressive, deterioration of their CVD
- Sudden cardiac arrest is rare!

Cancer Mortality Statistics

- Second leading cause of death in the U.S.
 - Accounts for 23% of all deaths
- American Cancer Society estimates that approximately > 585,720 people will die from cancer in 2014

Other Illnesses in Need of Palliation

- COPD
- Diabetes
- Alzheimer's disease
- AIDS
- Multiple sclerosis (MS)
- Amyotrophic lateral sclerosis (ALS)

Societal View of Death and Dying

DEATH = FAILURE



New Perspectives

“The final stage of growth”
Elisabeth Kubler Ross, 1975



Definition to Palliate

“to alleviate or to lessen the severity
without curing”
Webster, 2009

Definition of Palliative Care

- “The active total care of patients whose disease is not responsive to curative treatment. Control of pain, other symptoms, and of psychological, social, and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness, in conjunction with anticancer treatment.”

– World Health Organization, 1990

Palliative Care Is

- ✓ Excellent, evidence-based medical treatment
- ✓ Vigorous care of pain and symptoms throughout illness
- ✓ Care that patients want *at the same time* as efforts to cure or prolong life, when appropriate

Palliative Care Is NOT

- ✗ Not “giving up” on a patient
- ✗ Not in place of curative or life-prolonging care
- ✗ Not the same as hospice
- ✗ Does not require a DNR order (nor is that the “mission”)

IOM Report

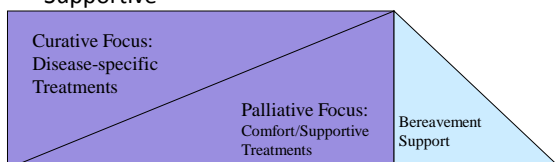
Dying In America

Clinician–Patient Communication and Advance Care Planning

- Patients at EOL cannot make their own decisions – ACP critical
- Most patients choose pain and symptom management over prolongation of life
- Open communication will focus on individual patient goals and preferences and avoid unwanted treatment
- Incentives, quality standards, and system support is needed to promote communication

Palliative Care Trajectory

- Active
- Symptomatic
- Supportive



Delivery of Person-Centered, Family-Oriented Care

- People nearing EOL experience multiple health care transitions
- Demand for family caregiving increasing
- Palliative care offers optimal QOL and possibly increased life expectancy
- Good evidence to manage symptoms available but adoption of care guidelines slow

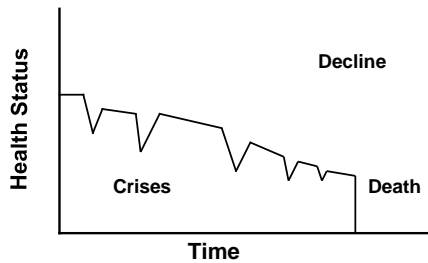
Professional Education and Development

- Improved with 3 remaining problems
 - Inadequate palliative care education in nursing and medical school curricula
 - Educational silos
 - Deficits in equipping physicians with communication skills
- Health care professionals not equipped to provide primary palliative care
 - Clinic setting

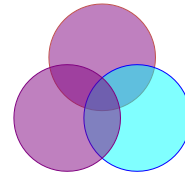
Roller Coaster

- 1985 - breast cancer
- 1995 – bone metastases
- 1998 – chest wall recurrence
- 2005 – vaginal wall recurrence
- 2008 – tumor around spinal cord that threatened functioning
- 2009 - soft tissue mass abdomen
- 2010 – lung and liver metastases
- Died in November 2011
- Nausea and vomiting with oral opioids
- Bone pain
- Abdominal (visceral) pain
- Osteonecrosis of the jaw
- Herpes zoster and post-herpetic neuralgia
- Fatigue, weakness, lack of energy
- Anorexia

Palliative Care Trajectory

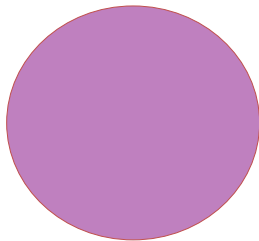


Innerconnectedness of the Body, Mind, and Spirit



Physical Care - Body

Physical Care of the Body



Symptoms Experienced by Patients At the End of Life

- Asthenia/Fatigue 90%
- Anorexia 85%
- Pain 75%
- Nausea 68%
- Constipation 65%
- Sedation and Confusion 60%
- Dyspnea up to 78%
- Xerostomia 7-10%

Overview of Delirium

- Concurrent disturbances of the level of consciousness, psychomotor behavior, memory, thinking, attention, emotion, and the sleep-wake cycle
- Incidence: up to 80%

Etiology of Delirium

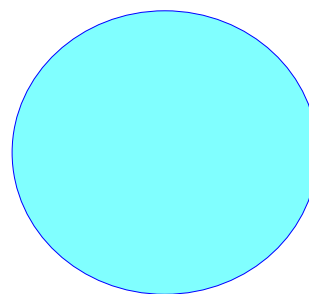
- CNS pathology
- Multiorgan failure
- Hyperhydration
- Hypercalcemia
- Medications
- Pain, dyspnea, anoxia
- Distended bladder

Pharmacologic Management of Delirium

- Treat the underlying cause
- Benzodiazepines
- Drug of choice: haloperidol
 - Found to sufficiently control delirium in advanced cancer
 - n=167 patients with a dx of delirium
 - 128 required therapy with haloperidol alone

MASCC, 2014; Candy et al., 2013

Psychosocial Care



Distress

- Prevalent throughout the cancer trajectory
- Barriers
 - Lack of assessment
 - Expected component of cancer
 - Reluctance to share concerns
 - Stigma of antidepressant therapy
- Signs and Symptoms
 - Depressed mood
 - Diminished pleasure
 - Change in appetite
 - Fatigue
 - Feeling worthless
 - Poor concentration
 - Suicidal thoughts
- How to measure
 - NCCN Distress Thermometer
 - Beck
 - HADS
- Psychoeducational and Psychosocial Interventions
 - CBT
 - Patient education
 - Counseling
 - Support groups
 - Massage
 - Music
- Pharmacologic Interventions
 - Antidepressants
 - Anxiolytics

Rawdin et al., 2013

Santa Visits Lisa

- Missed her Special Olympic Christmas Party while in the hospital
- Would not talk to the nurses that day
- And then . . .
- [Billings Clinic's Greatest Gift](#)

Lisa's Song

- Twinkle Twinkle Little Star
- Lisa, Lisa you have been
 - ICC's blessing, remember when
 - Rhonda's birthday and silly string
 - And your birthday cake and things
 - Lisa Lisa you have been
 - ICC's family, like next of kin.
- Thinking back, we had some fun
 - Santa's visit, and you collected mun\$\$\$
 - Selling tickets, for Special Olympics
 - Sparkling cider and anniversary kicks
 - Lisa Lisa you have won
 - ICC's award for special hun
- Lisa Lisa you have made
 - ICC's A+ grade
 - Needles, treatments, you are brave
 - Let's get together and do the wave
 - Lisa Lisa you are done
 - Now you go out and have some fun!!

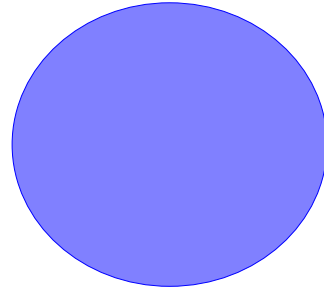
Building Memories

- Love Letters
- Audio Cassettes
- Video Taping
- Journaling
- Planning Your Own Funeral
- Writing Your Own Obituary
- Leaving a Legacy

Palliative Rehabilitation

- Art/Music Therapy
- Pet Therapy
- Clown Therapy
- Volunteerism
- Travel Therapy
- Shopping Therapy
- Camping Therapy
- Support Group Therapy

Spiritual Care



What is Spirituality?

- A personal search for meaning and purpose in life, which may or may not be related to religion
 - » Tanyi, 2002
- “Spirituality” is rarely used – difficult to understand
 - Stories about life
 - Relationships with self and others
 - Relationships with music and nature
 - Relationship with God or a higher being
 - Hope, meaning, and purpose in life
 - Religion

Edwards et al., 2010

“Rules may become a dead letter. It is the spirit of them that giveth life.”

Florence Nightingale, 1888



FICA Spiritual Assessment

- **F:** What is your faith or belief? Do you consider yourself spiritual or religious? What things do you believe in that give meaning to your life?
- **I:** Is it important in your life? What influence does it have on how you take care of yourself? How have your beliefs influenced in your behavior during this illness? What role do your beliefs play in regaining your health?
- **C:** Are you part of a spiritual or religious community? Is this of support to you and how? Is there a person or group of people you really love or who are really important to you?
- **A:** How would you like me, your healthcare provider to address these issues in your healthcare?

Puchalski, 2006

A Search for Meaning

- Past: experiences, successes, failures
- Present: understand current condition
- Future: what is going to happen to my family? where will I spend eternity?

Palliative Care Guidelines

Several
Multiple
Organizations

1. Palliative care for adults. 2015 (revised 2013) (NHS). NICE (2015).
2. Institute for Clinical Systems Improvement. NaylorG organization. View all guidelines by the developer(s)
3. Ethical practice guidelines for quality palliative care. 2004 (revised 2009 Jan). NICE (2012) (National Commission on Hospice). Medical Specialty Society. View all guidelines by the developer(s)
4. Palliative care for the patient with incurable cancer or advanced disease. Part 1: approach to care. 2010 (revised 2014). NICE (2014) (NHS). National Commission on Hospice. Medical Specialty Society. View all guidelines by the developer(s)
5. End of life care during the last days and hours. 2012 (revised 2010). NICE (2012) (NHS). National Commission on Hospice. Medical Specialty Society. View all guidelines by the developer(s)
6. Optimal palliative care: safe and effective prescribing of strong opioids for pain in palliative care of adults. 2012 (revised 2010). NICE (2012) (NHS). National Commission on Hospice. Medical Specialty Society. View all guidelines by the developer(s)
7. Palliative care: safe and effective prescribing of strong opioids for pain in palliative care of adults. 2012 (revised 2010). NICE (2012) (NHS). National Commission on Hospice. Medical Specialty Society. View all guidelines by the developer(s)
8. Best evidence statement (BES), Evidence based benefits of palliative care program on patient/family quality of life. 2009 (revised 2010). NICE (2010) (NHS). National Commission on Hospice. Medical Specialty Society. View all guidelines by the developer(s)
9. Lung cancer - The diagnosis and treatment of lung cancer. 2009 (revised 2011 Apr). NICE (2011) (NHS). National Commission on Hospice. Medical Specialty Society. View all guidelines by the developer(s)
10. Palliative and end of life care in lung cancer: diagnosis and management of lung cancer. 3rd ed. American College of Chest Physicians. Medical Specialty Society. View all guidelines by the developer(s)

It's Not Rocket Science

- The Problem
 - So why are patients still suffering?
 - Why is pain uncontrolled?
 - Why aren't patients getting early referral to palliative care?
- When Science Isn't Enough
 - Creative strategies
 - Positive deviance
 - Symptom Management Clinic

The Art of Symptom Management

- Pain other deleterious symptoms can be effectively controlled in >90% of patients
- When comfort is not attainable, palliative sedation for control of refractory symptoms is an option
- Let patients know we will not abandon them
- We hold the keys to patient comfort



Total Suffering – Total End of Life Care

