

The Continuum of Palliative Care

by

Jane S. Owen APN-BC, MSN, ACHPN, RN, C

Methodist University Hospital

Palliative Care Service

Memphis, TN

Objectives:

1. Describe the philosophy of Palliative Care.
2. Identify how trajectories of illness impact goal of care.
3. Recognize the realm of palliative care available in various health care environments.

The Patient's Good and the Ends of Medicine

“If medicine takes aim at death prevention, rather than at health and the relief of suffering, if it regards every death as premature, a failure of today's medicine-but avoidable by tomorrow's-then it is tacitly asserting that its true goal is bodily immortality... Physicians should try to keep their eyes on the main business, restoring and correcting what can be restored and corrected, always acknowledging that death will and must come, that health is a mortal good, and that as embodied beings we are fragile beings that must stop sooner or later, Medicine or no medicine. “

Kass LR. *JAMA* 1980; 224:1947

Historical Perspective

- Dying in America: late 1800's through early to – mid – 1900's
 - Focus was on comfort and watch-and-wait.
 - Healthcare systems worked with family in waiting and watching.
 - Hospitals changed the demographics, both of care and caregiving.

Scientific Imperative

Pharmacology - The development of penicillin, anesthetics, and intravenous therapy gave us interventions.

Technology – Dialysis, surgical treatment, and mechanical ventilation provided interventions.

Development of CPR

Big Question? When is it time to say when?

Historical Perspectives

- Cultural Changes
 - Higher standards of living, higher expectations from health care.
 - More care and treatment rather than comfort.
 - Immediate gratification.

Dying is no longer natural or normalized.

Everybody with serious illness spends at least some time in the hospital...

- 98% of Medicare decedents spend at least some time in a hospital in the year before death.
- 51-55% of decedents had at least one stay in an ICU in the 6 months before death.

Dartmouth Atlas of Health Care 1999

Death in Hospitals

- What do we know about it?
 - Physical suffering
 - Poor to non-existent communication about the goals of medical care
 - Lack of concordance of care with patient and family preferences
 - Huge financial, physical, and emotional burdens on family caregivers

The Nature of Suffering and the Goals of Medicine
Eric J. Cassell

- The relief of suffering and the cure of disease must be seen as the twin obligations of a medical profession that is truly dedicated to the care of the sick.
- Physicians' failure to understand the nature of suffering can result in medical intervention that (though technically adequate) not only fails to relieve suffering, but becomes a source of suffering in itself.

Palliative Care

...Palliative care improves the quality of life of patients and families who face life-threatening illness, by providing pain and symptom relief, spiritual and psychosocial support from diagnosis to the end of life and bereavement...

World Health Organization

Palliative Care Is:

- Planning ahead: Advance Care Plan
- Goal directed: Allow a natural death process.
- Excellent symptom management: pain, nausea, depression, secretions, dyspnea, agitation, anxiety,
- Empowering patients and families: through supportive and comprehensive communication
- Providing: spiritual, emotional, and psychological care

Living Well Until You Die

Palliative Care Is Not:

- | | |
|-------------------------|--------------------|
| - Giving Up | - Euthanasia |
| - Withholding Care | - Assisted Suicide |
| - Hopeless | - Hastening Death |
| - A piece-meal Approach | - Starvation |
| | - Unnatural |

Palliative Care Continuum

- Begins with the initial diagnosis of a life-threatening illness.
- Continues through the trajectory of illness.
- Ends with bereavement care for the remaining loved ones, which begins after the death of the patient.

Palliative Care Triggers

- Advancing age
- Chronic diseases (CHF, COPD, kidney failure, liver failure, cancer, dementia)
- Symptoms that interfere with daily life (shortness of breath, fatigue, pain, anxiety, nausea, anorexia)
- Frequent ER visits and/or hospitalizations
- Weight loss, falls, weakness, confusion
- Assistance with long-term planning and decision-making

Sarah's Journey

- Sarah is an 86 year-old widow who lives alone in a senior apartment complex. She had a history of CAD, CHF, OA, and HTN. She is fairly independent despite decreased hearing and low vision due to glaucoma.
- She has some urinary incontinence.
- She is no longer able to drive.
- She recently had difficulty keeping up with her finances and was noted to be more forgetful by the staff.

HOME

Palliative Care at Home

- Does she have an Advance Care Plan?
- Where are her family members?
- Who is her HCA?
- What are the triggers of the trajectory of illness?
- What physical symptoms does she exhibit?
- Is she sad or lonely?
- Has her PCP started any kind of discussion regarding her natural aging/decline process?

Goal: Maintain her level of function and medical stability

Sarah's Journey

- Sarah fell in her apartment on the way to the bathroom and fractured her right hip. Her neighbor found her the next morning.
- She was admitted to the hospital and had a right hip repair. She was quite confused during this hospital stay. It was difficult for her to participate in PT, and she did not progress well. Her son and daughter-in-law came in from Georgia to be with her.
- Discharge plans need to be made.

HOSPITAL

In-patient Palliative Care

- Does the family understand the trajectory of illness?
- Are they aware of the multiple co-morbidities?
- Is her Advance Care Plan completed with a HCA designated?
- Are her symptoms under control?
- Are the psychosocial needs of the patient and family addressed?

Goal: Return to highest level of function achievable.

Treat her pain.

Sarah's Journey

- She is transferred to a skilled nursing facility for additional therapy with the hope that she will be able to return to her apartment at some time.
- She has more periods of confusion and now has a decreased appetite. Her weakness and fatigue preclude any real progress in PT. She is not sleeping well, and her pain is increasing. After two months, it is obvious that she will not be able to return to her apartment. She is steadily declining and has lost her functional abilities despite therapy.

Goal: Improve her level of comfort.

SKILLED NURSING FACILITY

Long Term Palliative Care I

- Would you be surprised if Sarah lived another 6 months? Another year?
- Prognostic Scales are helpful
 - Flacker and Kiely's Assessment Tool
 - Predicting 6-month mortality in NH residents with advanced dementia
 - Karnofsky Performance Status
 - Risk of death within one year of discharge in hospitalized older adults.

Long term Palliative Care II

Family Conference: Decided on symptom management and comfort care approach.

Weight loss is expected.

Worsening of dementia is expected.

Continued decline in functional ability is expected.

Decrease food and fluid intake is expected.

Staff Conference: Aware of Palliative Care approach.

Periods of rest, music at bedside, aromatherapy, reminiscing, healing touch, oral care.

Talking the “Talk” of Palliative Care

- Allow Natural Death (AND) vs Do Not Resuscitate
- Inappropriate care vs futile care
- Does the treatment plan meet the goals of care?
- Let nature take its course vs withdraw care.
- Talk about the “big picture” vs organ reports.

Walking the Walk

- Professional healthcare providers must understand and utilize the concepts of Palliative Care.
- Teaching patients/families about living well until they die is as important as teaching prenatal, neonatal, disease management, and health maintenance.

“To everything there is a season, and a time to every purpose under heaven: a time to be born and a time to die.”

Ecclesiastes 3:1

Caring Conversations: The Mainstay of Palliative Care

- **Background:** What do you know and understand?
- **Affect:** How do you feel about what is happening?
- **Trouble:** What about this situation troubles you?
- **How are you doing?**
- **Empathy:** I know this must be very difficult for you.

POST/POLST

- Physicians Orders for Scope of Treatment
- www.health.state.tn.us/
- Physicians Orders for Life Sustaining Treatment
- www.polst.org

References/Resources

Center for Advance Palliative Care www.capc.org

EPERC (Education of Physicians for End of Life Resource Center)
Fast Fact and Concepts www.eperc.mcw.edu

Henderson, M., Hanson, L., Reynolds, K. (2003). *Improving nursing home care of the dying*. New York: Springer Publishing Company.

Hospice and Palliative Nurses Association www.hpna.org

Matzo, M. (2004). Palliative Care: Prognostication and the chronically ill: Methods you need to know as chronic disease progresses in older adults. *American Journal of Nursing*, 104 (9), 40-49.

National Hospice and Palliative Care organization
www.nhpco.org