UNE SALLE DE L'HÔTEL-DIEU AU XVIᵉ SIÈCLE
Why Hospice and Palliative Care?

- Yale oncologist
- Georgetown’s patient with abdominal surgeries
- Carlos’ patient still receiving chemotherapy
- My brother
Emergence of Hospice

• Dame Cicely Saunders founded St. Christopher’s Hospice in London in 1967.
• Hospices were, in Saunders’s view, a stopping off place for pilgrims on death’s journey—and for those who accompanied them on their journeys. They were places where the pain of the dying and their families could be attended to—the whole of their pain—their physical, psychological, social, and spiritual pain.
Emergence of Palliative Care

- Balfour Mount, MD, urologist, surgical oncologist
- 1975, Director of Palliative Care Royal Victoria, Montreal
- "It didn't occur to me that I didn't have a clue about death and dying," says Dr. Mount, who had dealt with a bout of testicular cancer a decade earlier at the age of 24, and had been forced to confront his own mortality. "I thought, 'I'm a doctor; I must know everything in the world about death and dying.' But, of course, I knew absolutely nothing."
  — Ottawa Citizen, 2005
- “challenge of addressing the needs of the dying when others chose not to”
20th Century

• Diseases once quickly fatal are now slowly fatal

• Medical technology
  – May foster the illusion of immortality
  – Offers no guidance with how to value the time between diagnosis and death
Living with, dying from chronic illness

• 90 million Americans live with a chronic illness
  – 7/10 die from a chronic illness
  – Medicare: 9/10 who die have one of nine chronic illnesses:
    • congestive heart failure,
    • chronic lung disease,
    • cancer,
    • coronary artery disease,
    • renal failure,
    • peripheral vascular disease,
    • diabetes,
    • chronic liver disease, and
    • dementia

• Patients in their final year of life account for 32% of total Medicare spending, especially
  – Physician bills
  – Hospital fees
How patients die

• More inpatient care is related to
  – more aggressive care,
  – seeing medical specialists more frequently,
  – spending more days in the hospital, and
  – dying in an ICU

• Patients who receive more intensive inpatient care
  – do not have improved survival,
  – do not have better quality of life, or
  – do not have better access to care than patients who live in communities where they receive less care.
Definitions of Palliative Care: World Health Organization (WHO)

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. 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;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, 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.

– http://www.who.int/cancer/palliative/definition/en/
Definition: National Hospice & Palliative Care Organization

- NHPCO's *Standards of Practice for Hospice Programs* describes palliative care as:

- Treatment that enhances comfort and improves the quality of an individual’s life during the last phase of life. **No specific therapy is excluded from consideration.** The test of palliative care lies in the agreement between the individual, physician(s), primary caregiver, and the hospice team that the expected outcome is relief from distressing symptoms, the easing of pain, and/or enhancing the quality of life. The decision to intervene with active palliative care is based on an ability to meet stated goals rather than affect the underlying disease. An individual’s needs must continue to be assessed and all treatment options explored and evaluated in the context of the individual’s values and symptoms. The individual’s choices and decisions regarding care are paramount and must be followed.
  
  – http://www.nhpco.org/i4a/pages/index.cfm?pageid=4648/
Palliative Care – Definitions

• “Synonymous with hospice” (Levy, 1985)
  – No longer accurate
• “Total active care of patients and families...when the patient’s disease no longer responds to curative treatment.” (WHO, 1990)
  – Cannot apply during curative therapy
• “Comprehensive, multidisciplinary supportive care for patient and family throughout the continuum of advanced illness.”
Palliative care interventions focus on:

• Management of pain and other debilitating symptoms
• Attending to psychological, spiritual and social issues dimensions of illness
• Assisting patient, family and primary physician with decision-making and quality-of-life issues
Palliative Medicine Consultation

- Palliative “thinking” begins with the diagnosis of a life-threatening illness
- Palliative consultation should be considered when symptom management, advance care planning and psychosocial issues *predominate*:
  - The patient’s needs
  - The family’s concerns
  - The doctor’s time, effort and thinking
Palliative care: A broad category

• Differs from “hospice”
  – Does not require a specific prognosis
  – Does not require waiving insurance benefits
  – Applicable throughout the continuum of illness

• Can be used concurrently with:
  – Curative interventions
  – Life-prolonging treatment
  – Clinical trials
Palliative Care in the 21st century

- Aggressive symptom management
- Supported decision making
- End of life care
- Family centered
- Interdisciplinary
• All end of life care is palliative.

• Not all palliative care is end of life care.
Hospice Data

• The NHPCO estimates that 1.65 million patients received hospice services, and 44.6% of all deaths were under the care of a hospice program.

• Data from 2009 show that a quarter of hospice care was for three days or less, with 40% of those late referrals following a hospitalization with an intensive care stay.
Palliative Care Data

• As of 2012, the number of hospitals with a palliative care team increased from 658 (24.5%) to 1635 (65.7%), an increase of 148.5% from 2000–2010. The largest growth has been in the Northeast and South. Nearly 90% (87.9%) of hospitals with 300 or more beds have a palliative care team.
Major challenges facing the expansion of palliative care services for those with life-limiting illnesses

- Limited work-force capacity of health care professionals trained and certified to care for the growing population of the elderly.
- Educating the public about palliative care as a continuum of care, clarifying that it is care that matches treatment with patients’ goals and that it is not just focused on end-of-life care or hospice services.
- Growing concern that palliative care services may reduce rather than expand referrals to hospice care. Competition is starting to pit one against the other and could derail both movements.
- Making palliative care available for all who need it. That implies a public who knows what palliative care is and demands it. Foley, 2014.
Hospital-based Palliative Care Service

Case Scenario

• This 64-year-old female patient is married with two daughters, 31, 28 and a 12 year old son. Her oldest daughter described her father as “alcoholic and incapable of self-care” and stated that the marriage should have been over before any of the children were born.

• The patient was diagnosed with Acute Myelogenous Leukemia and on the same day was admitted to the hospital and treated with chemotherapy. While the therapy sent her into remission she developed renal and pulmonary failure and had fluid abscesses culturing positive in her abdomen necessitating a two month long stay in the medical intensive care unit during which time the family all said their good-byes not expecting her to survive.

• She is now extubated and moved to a general oncology floor. She is very clear that she is tired of suffering and wants to die as soon as possible. “I am desperate, desperate, desperate! All I’ve heard are false promises.” She is receiving dialysis 3x weekly, which she finds particularly stressful especially since no one can give her an exact time for the treatments. Her nights are endless.
• Her abdominal abscesses are being cultured to see if she can be given another course of chemo. She is in remission, but her protocol calls for another round of chemo within a relatively tight time frame. She is already beyond the optimal time for this consolidation therapy. Her age and cytogenics are negative prognostic factors. No one on the medical team can say exactly what the prospects of meaningful survival are and estimates vary. Another infection post therapy when her white blood counts would be down was certainly likely.

• This patient is the president and chief executive of a highly successful international financial corporation and is definitely used to being in charge. Her inability to manage her days in the hospital is creating huge anxieties for her. Her two daughters are constantly in attendance, including one of them during the night. They are intelligent and committed to securing their mother’s best interests... but they definitely do not want her to give up. The patient’s two brothers are even stronger about the patient’s need to fight. All seemed to believe that the mother should be concerned about being there for her 13 year old son who needs her.

• The children believe that depression is interfering with the mother’s will to fight. How should the physician respond when asked by the patient to end her life?
• Who is the appropriate decision maker? Does the patient have the capacity to make valid health care decisions?
• What criteria should be used to determine treatment goals and an appropriate plan of care?
• Can the physician honor the patient’s request to be euthanized/killed?
• At present dialysis and total parenteral nutrition are keeping the patient alive. Can one or both of these be stopped?
• The patient’s existential angst/extreme emotional suffering was her most distressing symptom—and she had not responded well to sedative management. Should palliative sedation to unconsciousness (PSU) be used to render her unconscious?
• At what point should the palliative care service be involved and what treatment goals and care priorities would you expect from the palliative care service?
Janet is a 65-year-old woman who has battled cancer for 27 years—with five major recurrences. Her husband died early and she raised two wonderful sons. She buried her mother and a sister. She is Lutheran and played the organ for her church for years. Now she is tired, tired, tired. For years she fought the cancer wanting to raise her sons, get them through college, and see a grandchild. But at present she is finding life too threatening and she wants to “go to God.” She has researched her options on the Internet and comes to hospice wanting “palliative sedation.” Her sons support her. The hospice has a policy which states that palliative sedation needs to be used for the imminently dying and that it should not be used to treat existential suffering or angst. Janet does not meet these criteria. When she is told that palliative sedation is used for intractable pain, delirium, agitation, dyspnea, and then asked to evaluate her pain on a scale of 1 (no pain) to 10 (worst pain) she says her pain is about a 1 or 2. She says that she will not commit suicide because she does not want her sons to have to live with this legacy. She also says that she does not want to stop eating and drinking because this will “drag” on for days. Staff report that she uses lots of “code language” and winking seeming to suggest that she knows they cannot give her a lethal prescription because assisted suicide is illegal in their state but that they should be able to accomplish the same thing via palliative sedation. Some of the staff are angry that she wants them to do what she will not do for herself. Others believe that the hospice policy is wrong and that palliative sedation should be allowed for existential suffering since it most certainly is a “distressing symptom.” What recommendations should come from the hospice ethics committee or consultants about meeting Janet’s needs?
Home/Nursing Home-Based Hospice Service Case Scenario

- George is a 77 white male who has been diagnosed with Lewy Body Dementia, characterized by aggression and depression. His wife Pat has been called eight different times to have him removed from nursing homes because of his aggression. He is eventually admitted to a free standing hospice whose geriatrician is confident that with appropriate medical management his symptoms can be ameliorated. While George’s aggression has been resolved it came at the cost of his general functioning and George now requires help with activities of daily living. It is now one year later and home hospice continues to follow him in a nursing home. His wife is repeatedly asking the nursing home staff not to hand feed him. “Bring him his tray and set it down in front of him, but if he doesn’t eat, don’t help him. He would never want to live this way.” George has an advance directive which specifies that under certain conditions he would not want artificial nutrition and hydration, but his directive says nothing about hand feeding. The nursing home staff are very concerned about not feeding George because George seems to enjoy meal times.
Free Standing Hospice Case Scenario

- Mary is an educated, articulate, wealthy and until recently, healthy 80 year old, single woman. She has lived a rich and full life and sees nothing but diminishment in her future with a life increasingly constricted to her apartment. She does have advanced osteoporosis. A recent fall resulted in a leg fracture. When she told someone that she wished she could just fall asleep and never wake up, her friend told her that she should just stop eating and drinking. Her friend works for hospice and Mary is now asking this hospice to care for her until she dies. The medical director has asked the hospice ethics committee to make a recommendation about the advisability of admitting Mary to the inpatient hospice unit so she can be cared for as she grows weaker. No one doubts Mary’s decision-making capacity. Mary is single and has no family. None of her friends believes she is doing the right thing and no one is willing to care for her as she dies. Initial responses from the hospice senior management team were varied. “No way should we be doing this… Mary is killing herself and asking us to be complicit.” “There must be lots of folks who need help like this; perhaps we should develop this as a new product line.” There were also questions about whether or not hospice physicians and nurses should start recommending terminal dehydration to patients like Mary who want to be dead but who do not have life-sustaining treatments to stop.
References

City of Hope Pain and Palliative Care Resource Center. [http://prc.coh.org/qual_life.asp](http://prc.coh.org/qual_life.asp)


