End of Life Care

Refers to healthcare not only of patients in the final hours of their lives, but more broadly care of all those with terminal illness or terminal condition that has become advanced, progressive, and incurable. They may present in your emergency room for you to see.
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... is a very personal experience
  • For the Patient
  • For the Family
  • For the physician

The personality of the patient; meeting the personality of the physician. Often is the dying patient talking with a living physician and caretakers. Each human being has unique needs for information and support.
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Centered around the following issues:

• Human and Religious elements
• Ethical and moral elements
• Medical care
• Legal issues
• Economic cost
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May be:

- **Expected**
  
  A deeply personal experience
  
  COPD Patient Dying

- **Unexpected**
  
  Hectic medical interventions
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Signs of Expected End of Life:

- Drowsiness and unresponsiveness
- Confusion about place, identity, and loved ones
- Decreased socialization and withdrawal
- Decreased need of food and fluids
- Skin cool to touch, may be bluish in color
- Gurgling sounds with breathing
- Difficulty consoling pain
- Involuntary movements
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Signs of Unexpected End of Life:

- Usually patient coming to Emergency Room in cardiac, respiratory, or traumatic arrest
- Usually they are patients in their prime years of life
- Heroic interventions are needed to save them

Case Study – “Don’t let him die...”
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End of Life Care – Human Element:

• Death has not changed, but dying has
• Dying is quite different from what it used to be thanks to medical technologies: Extended Life – more lingering process than sudden death
  • People on dialysis for over 20 years
  • Incurable cancers chemotherapy
  • Car accidents/ Head trauma/ On respirators and feeding tubes
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Good Death:

• Spiritual, religious, and cultural beliefs and practices play a significant role in lives of patients dying
• Inferred treatment choices are distinct from choices expressed by patients themselves
• A common goal should be to provide a meaningful dying experience – Good Death
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Human, Religious Element:

A study of over 2,000 patients used religion to cope with end of life care from questionnaires and interventions, patients were followed until death averaged four months after enrollment.

• 4 out of 5 patients reported that religion helped to cope to a moderate extent or more
• 1/3 of patients agreed with statement, “It is the most important thing that helps me going.”
• More than 55.9% reported praying, meditating, or studying religion daily

Pringerson
Religious Study End of Life Care
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Human, Religious Element (cont.):

• Patients with high level of religious coping were more likely blacks and Hispanics, less educated, less likely to have medical insurance or married than patients who reported low reliance on religion.
• Patients with high level of religious coping
  - 11% had medical ventilation during last week of life
  - 7.4% underwent CRP
• Patients with low level of religious coping
  - 3.6% had medical ventilation
  - 1.8% underwent CPR
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Good Death

• Dying good – Important goal for physicians and members of care team
• What people choose as good death is often beyond what medicine can provide
  - Affirmation of love
  - Completion of important work
  - Last visit with important person
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Good Death (cont.)

The physicians goals should be:

- Control pain or other physical symptoms
- Involvement of people important to the patient
  - Death usually is not an individual experience
- Medical understanding of patients’ disease
  - Need for medical information
- Process of care
  - Coordinating systems of providers
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Good Death (cont.)
- What physicians should understand

• The patient’s story
  • How that person has viewed their life; what is important
• The body
  • Understanding the disease limits and possibilities
• The medical care system available
  • How it can work for the patient; hospice care, laws, and ethics
• Finally you must understand yourself
  • You can help or damage the interaction

Support Study
Joan Lynn
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Withholding Treatment

- 85 year old man with severe progressive COPD enters an emergency room for treatment in severe respiratory compromise, elevated PCO2 acidotic, hardly talking, obtundent, needs to be incubated – how do you proceed.
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Withdrawing Treatment

- Beth Cruzan, 32 year old woman, in permanent vegetative state (PVS) after car accident, the parents petitioned the withdrawal of her feeding tubes and let her die. The Missouri State Supreme Court ruled that life sustaining treatment could not be withdrawn.
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Withdrawing Treatment (cont.)
Landmark decision by the United States Supreme Court in Beth Cruzan Case states that

- Competent patients have a “constitutionally protected liberty refusing treatment”.
- All medical treatments are regarded as ethically and legally equivalent. Patients have the right to refuse treatment of whatever kind.
- Patients do not have the right to demand futile treatment that cannot achieve the stated goal.
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Autonomy

- Anglo-American culture and medical ethics is centered around patient Autonomy – patients have the ultimate right to decide for themselves what should or should not be done with them. Therefore, Truth Telling respects autonomy. Failure to provide truth by physicians is failure for patients to exercise their autonomy (this principle is controversial in some cultures).
- In many countries and ethnic communities physicians and families often feel that withholding medical information is in the best interest of the patients for hope and security. Truth concealing can be difficult for treating physicians and caring families. Cultural beliefs, however, play a great role in suffering and dying.
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Autonomy (cont.)

• In the Anglo-American tradition autonomy – the right to make choices about one’s own life is a basic principle. However, competence must be established for this principle.

• Competence is measured by:
  - Ability to communicate
  - Ability to understand proposed treatments
  - Ability to grasp consequences of that treatment
  - Ability to reason
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Advanced Planning

- Once competence is established the patient chooses a **surrogate** usually next of kin or any other person who will represent the patient legally if the patient is incompetent.
- Once a patient is determined incompetent and has no surrogate, a **guardian** is assigned by a judge in court to be legally responsible to direct the patient’s medical care. A guardian is also used when multiple family members cannot agree in the specific care of the patient.
- Advanced care planning involves
  - Healthcare proxy
  - A living will
  - Institutional derivatives
  - POLST, MOLST
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- **Healthcare Proxy** (durable power of attorney). The surrogate or guardian legal right to direct all care for the incompetent patient.
- **Living Will** it is the medical wishes of a still competent patient, directing his/her care when they become incompetent. What he/she should do or not due with the patient.
- **Institutional directives**
  - **POLST** – physicians orders for life sustaining treatment
    - Patient preference for end of life recorded in highly visible standardized form.
    - It is immediately available and recognized, can be used by doctors, paramedics, police, fire departments, emergency rooms, hospitals, and nursing homes.
    - In some states also known as MOLST. These forms are used in 26 states.
    - POLST is voluntary and must be signed by a competent patient.
  - **DNR or DNAR** – do not attempt to resuscitate is a limited directive of patient wishes not to have cardio-pulmonary resuscitation.
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DNR Form

POLST Form
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Assisted Suicide – Euthanasia

- **Assisted Suicide** – suicide committed with the assistance of another person.
- **Euthanasia** – is killing another person in order to relieve severe suffering, is a physician aid in dying – lethal dose of medication upon patient request.
- Still controversial in many countries.
  - Illegal – Germany, England, Hungary, France, and many other countries
  - Legal – Luxemburg, Holland, United States (Oregon, Washington, Montana, and Vermont).
- Study National Survey of Physicians Assisted Suicide and Euthanasia in the United States (NEJM 1996)
  - 3,102 physicians were asked about euthanasia, 1,902 responded
    - 60% responded they would do it if legalized
    - 4.7% responded they’ve administered at least one lethal injunction

“We don’t allow animals to suffer, why should we allow humans?” – Stephen Hawking
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Hospice Care

• Hospice care is a type and philosophy of care that focuses on palliation of a terminally ill patient. Attending to pain and symptom control with their emotional and spiritual needs.
  • In 2010 estimated 1.5 million patients receive services of hospice care.
  • In the US 41.9% of that were in hospice program
  • Average length of service 67.9 days
  • 66.7% received hospice care at home, 21.9% in hospitals, 14% in nursing homes
  • 82.7% were over 65 years old
  • By diagnosis – Cancer 35.6%, Non-Cancer 64.4% (heart disease, lung disease, dementia, stroke, etc.)
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Hospice services provided regardless of the insurance type.

- **Nursing Services** nurse visit 1-3 days per week, access to 24 hour on call.
- **Physician participation** – patients are cared for by their regular physicians in cooperation with the hospice medical director.
- **Counseling Services** – may include pastoral or spiritual support for patients and families up to 1 year after death.
- **Home health aide services** help patients with their personal care
- **Medication** covers all medication intended to alleviate symptoms.
- **Medical Equipment** – equipment necessary at home (hospital bed, wheelchair, oxygen, etc.)
- **Other medical supplies** – diapers, bandages, gloves, etc.
- **Laboratory and other diagnostic studies** related to terminal illness.
- **Therapist**, physical therapy, occupational therapy, speech therapy.
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Hospice Care - misunderstandings and myths

- Hospice care means giving up hope. It is not giving up hope, it is redefining hope. Once hope meant cure, now hope means being pain free, seeing a distant friend relative, taking a trip, spending time with loved ones.
- Do I have to sign a DNR order? No it is not required for hospice care.
- Hospice is only for cancer patients. No 51% of hospice patients are non-cancer patients, they have chronic conditions.
- Hospice is only for patient dying. No the dying process takes time. Hospice care is a teamwork to support the dying, it is not a death sentence. (Average length of stay is 20-60 days)
- Some family members out of guilt insist “everything that can be done should be done”. They believe that failure to do so is killing the patient.
- Modern technologies in medicine can extend life but Dr. Gordon, famous physician, says “I wish more people knew the misery of everything.”
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Hospice Cost rates estimated under Medicare (2011-2012)

- Routine homecare estimated at $151.23 per day
- Inpatient hospice care is $164.44 per day
- General inpatient care $671.84 per day

Total End of Life Cost

- US total end of life care more than $600 billion per year. Top 5% of patients account for more than half of the spending.
- Medicare annual budget $327 billion, more than 1/3, $88 billion, is spent for the last year of life.
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Hungarian Perspectives, PHD thesis by Agnes Csikos
University of Pecs 2011

• Dead and dying are taboo topics in Hungary.
• The care of the dying, symptom relief, spiritual and psychological support to patients and relatives are not well addressed.
• 845 unselected patients from 29 adult primary care offices completed a questionnaire.
• Results
  • Majority of Hungarian prefer end of life care at home (69%)
  • 19% prefer to die in hospitals
  • Responders greatest fear was loss of their autonomy and depending on caregiver (55%)
  • Second noted concern was fear of pain in suffering (38%)
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Comparative Study of American and Hungarian Family Physician Aptitude toward End of Life Care

- Questionnaires were sent to all primary care physicians at Baranya county (339) and Summa county, Ohio (300)
- Response rate was 54% in Hungary and 48% in the United States.

Results
- 58% of US physicians stated they were knowledgeable about hospice care, compared to only 9% in Hungary
- 71% of US physicians rated services for terminally ill patients as exceptionally good, compared to 1% of Hungarian physicians.
- Physician belief about terminally ill patient maintain dignity, US 60%, Hungary 41%
- Discussion of terminal prognosis with patient leads to hopelessness, 7% US physicians felt this was the case, 55% of Hungarian physicians.
- Hungarian physician disclosed when asked 40%, US physician 77%, always tell the patient their diagnosis.

Csikos MD Study
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Conclusion

• Dignity
• Autonomy
• Empathy

More than Sympathy

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To be, or not to be, that is the question:  
Whether ’tis nobler in the mind to suffer  
The slings and arrows of outrageous fortune,  
Or to take arms against a sea of troubles,  
And by opposing end them? To die: to sleep;  
No more; and by sleep to say we end  
The heartache and the thousand natural shock  
That flesh is heir to, ’tis a consummation  
Devoutly to be wish’d. To die, to sleep;
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...And for those of you who believe in the hands of God we rest