End of Life Issues in Psychiatry

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End of Life Issues in Psychiatry

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Learning Objectives

1. Know the goals of hospice and palliative care.
2. Understand the evolution of palliative care psychiatry.
3. Know psychiatry's role in hospice and palliative care medicine.
4. Help differentiate between grief, adjustment, major depression and demoralization.
5. Know psychiatry's role in end of life discussions and physician aid in dying.

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End of Life Issues in Psychiatry

Because I could not stop for Death, He kindly stopped for me.

Emily Dickinson

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Thanatophobia

The extreme and often irrational thought or fear of death or the unknown

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Outline

- **What is Life & Death…???**
- **What is Hospice?**
- **What is Palliative Care?**
- **Psychiatry's Role in Hospice Palliative Care Medicine (HPCM)**
- **Psychiatry & Physician Aid in Dying (PAD)**
- **End of Life Discussions**
- **Health Care Costs at End of Life**
- **Quality of Life at End of Life**
- **Questions & Answers**
- **References**

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Interpretation of Life & Death[1]

All that Man Is by David Szalay

"From somewhere, an image has entered Simson's head, an image of human life as bubbles rising through water. The bubbles rise in streams and clouds, touching and mingling and each remaining individually defined as they travel upwards from the depths towards the light until at the surface they cease to exist as individual entities. In the water, they existed physically, individually. In the air, they are part of the air, part of the endless whole, inseparable from everything else. Yes, he thinks, squinting in the mist-softened sunlight, tears filling his eyes. That is how it is – life and death."

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What is Hospice?

- Team based
- Poor prognosis < 6 months* (terminal)
- No longer curative
- Payor source

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What is Hospice?

- Hospice focuses on caring, not curing and in most cases care is provided in the patient's home
- It may be provided in freestanding hospice centers, hospitals, nursing homes or other long-term care facilities
- Typically, a family member serves as the primary caregiver and, when appropriate, helps make decisions for the terminally ill individual

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Into the Abyss

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Who are the Hospice Team?

- Hospice team develops a care plan that meets each patient's individual needs for pain management and symptom control. They make regular visits, as well are on call 24/7. Includes:
  - Patient's PCP
  - Hospice physician (or medical director)
  - Nurses
  - Home health aides
  - Social workers
  - Clergy or other counselors
  - Trained volunteers
  - Speech, physical and occupational therapists, if needed

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Circle of Death

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What are the Goals of Hospice?

- **Manage the patient's pain and symptoms**
- **Assist the patient with the emotional, psychosocial and spiritual aspects of dying**
- **Provide needed drugs, medical supplies and equipment**
- **Coach the family on how to care for the patient**
- **Deliver special services like speech and physical therapy when needed**
- **Make short-term inpatient care available when pain or symptoms become too difficult to manage at home, or the caregiver needs respite time**
- **Provide bereavement care and counseling to surviving family/friends**
  - National Hospice & Palliative Care Organization (nhpco.org)

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What are the Goals of Hospice?

Cure sometimes, treat often and comfort always.

Hippocrates

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Underuse of Hospice Care[2,3]

- More ~90% of US adults say they would prefer to die in their home
- But ~1/3 of Medicare patients actually die at home
- Newer research suggests that the US has perhaps the highest level of hospice capacity and use, as well as the highest likelihood of death at home in the developed world
- However there is still clearly a common missing element: Lack of *earlier* end of life discussions and use of advance care directives (i.e. living wills)

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What are Advance Care Directives?

- **Patient directed even if patient is unable to communicate**
- **May reduce emotional distress of decision-making for families**
- **May reduce financial burdens**
- **May reduce "aggressive care" at end of life:**
  - **multiple ER visits**
  - **ICU admissions**
  - **resuscitations**
  - **ventilator support**
  - **chemotherapy near death**
  - **feeding tubes**
- **May decrease likelihood of in-hospital death**

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Underuse of Hospice Care[2,3]

- Of all Medicare beneficiaries who died in 2013 47% used hospice, a rate more than doubled since 2000 (23%)
- Hospice use increases with age, highest rates existing among decedents ages >85 years old
- Hospice use is higher among women than men, and higher in whites than minorities
- Hospice care accounts for about 10% of traditional Medicare spending in beneficiaries' last year of life

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Underuse of Hospice Care[2,3]

- Atul Gawande, MD, MPH (Ed. *JAMA* Jan 2016)
- *On the national level, eligibility for hospice services has continued to be a major barrier.*
- *Medicare and private insurers have codified benefit limits that require patients to give up on curative therapy in order to receive the intensive palliative services and management of hospice.*
- *The recent Medicare demonstration project testing the lifting of those limits with 114 hospice organizations across the country will hopefully show cost reduction and better patients' health.*

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Inequality of Hospice Care[4]

- National Health Care Quality and Disparities Report: Chartbook on Healthcare for Blacks February 2016
- Commemorates the 30th Anniversary of the Report of the Secretary's Task Force on Black and Minority Health (Heckler Report)
- Summarizes trends in health care disparities by race related to access to health care and priorities of the National Quality Strategy

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Inequality of Hospice Care[4]

- Overall in 2014, 90.7% of hospice patients reported receiving the right amount of help for feelings of anxiety or sadness
- In 2014, blacks and other minorities were significantly less likely to report this help
- Overall in 2014, 94.8% of hospice patients reported receiving care consistent with their stated end of life wishes
- In 2014, blacks and other minorities were significantly less likely to report this care

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What is Palliative Care?

"Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threating 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."

- **World Health Organization**

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Broad Goals of Palliative Care

- The care model encompasses specific components of care based on evidence-based medicine and best practices, delivered across thespectrum of disease.
- It crosses the continuum of site of care including home, hospital, outpatient clinics, provider's office or community setting.
- It promotes effective provider communication and coordination.
- Care model uses a patient-centric, team approach and a focus on prevention and self-management.
- Its foundation is the Triple Aim (customer experience, health outcomes, and affordability).

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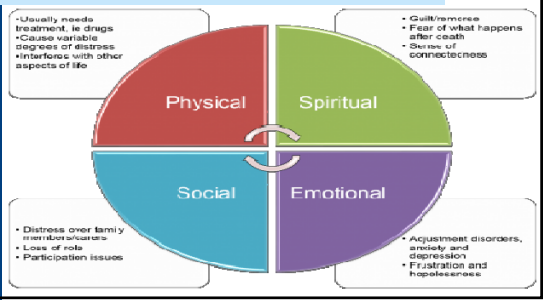
Specific Aims of Palliative Care



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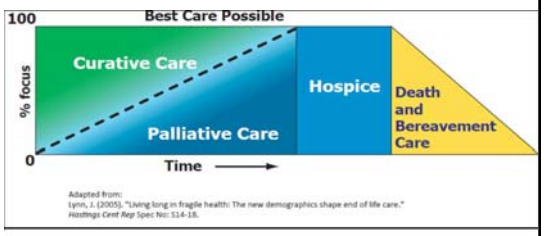
Best Continuum Model for HPCM



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Palliative Care Psychiatry

- Evolution of palliative care psychiatry
  - Cancer care → hospice care
  - Hospice care → palliative care
  - Psychiatry → psychosomatic medicine → psycho-oncology
- Palliative care psychiatry = intersection of hospice care, palliative care, psychosomatic medicine + psycho-oncology

Dr. Scott Irwin, M.D., Ph.D.
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Palliative Care Psychiatry Program

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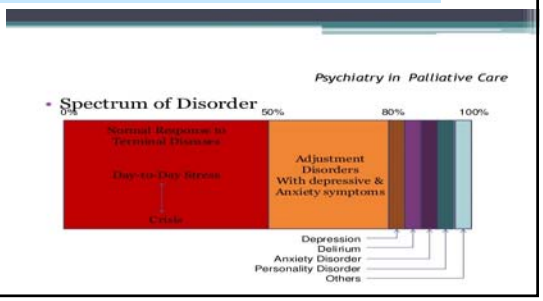
Psychiatry's Role in HPCM



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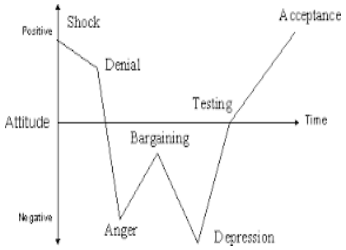
Psychiatry's Role in HPCM



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Psychiatry's Role in HPCM[5]

- Studies suggest that depression in the terminally ill range from 25% to 77% (~50%)
- In a retrospective study by Dr. Irwin et. al in ~3,000 patients, depression was documented in only 10.8% of those receiving home hospice & only 13.7% of those receiving inpatient care
- What are the reasons for this underdiagnosis and failure to initiate treatment in this population?

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Psychiatry's Role in HPCM[5]

- Some doctors may feel that depression is an appropriate reaction to the process of coming to terms with death and dying
- Some doctors might be uncomfortable with available treatment options and adverse drug interactions
- Some doctors may distance themselves from patients because they are uncomfortable
- Some patients may choose to keep their depression hidden preventing accurate diagnosis

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Psychiatry's Role in HPCM[5]

- Failing to respond adequately to the problem of depression can interfere with one's capacity to make decisions about his or her own care
- It can interfere with relationships, achieving one's final goals, as well as meaningful and peaceful end of life experiences
- It can worsen pain/symptom management, while increasing rates of hospital admission and shorten time to death

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Psychiatry's Role in HPCM[5]

Question: Psychiatrically, what is the difference between a good life and a good death?

Answer: "It means to be as free from psychiatric issues at any stage of life–or at the very least have them addressed and attended to."

Dr. Scott Irwin, M.D., Ph.D.
Medical Director University of California San Diego Palliative Care Psychiatry Program

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Psychiatry's Role in HPCM[6]

- So is it appropriate grief, mild depression, major depression or demoralization? How to we approach & treat these different conditions?
- Addressing existential concerns is a core component of palliative care
- The 4 key existential domains pertinent to palliative medicine have been proposed by Kissane et al. which include:
  - **The self, free choice, anxiety and meaning**

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Psychiatry's Role in HPCM[6]

- Demoralization is prevalent in up to 1/3 of medically ill patients
- While demoralization is frequently encountered, the DSM does not list criteria for it and as such the definition varies depending on the source and is still considered to be evolving
- Demoralization may be characterized by prolonged meaninglessness, helplessness and hopelessness that foster such intense existential despair that one may entertain "hastened death"

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Psychiatry's Role in HPCM[6]

- Demoralization and depression share many features in common, including sadness, vegetative symptoms and even *suicidal thinking*
- However, anhedonia is one of the hallmarks of a major depressive episode that is absent in demoralization
- A demoralized patient maintains the ability to experience pleasure and enjoyment when he or she is not confronted directly with the reality of his or her illness

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Psychiatry's Role in HPCM[6]

- While pharmacology and/or psychotherapy is the treatment for depression, *skilled* psychotherapy is the treatment of choice for demoralization
- Common themes include: confiding relationship, healing setting and a conceptual scheme or myth that provides a plausible explanation for the patient's symptoms, as well may prescribe a ritual or procedure for resolving them
- Main goal is to reconnect the 4 key existential domains & develop a person's sense of meaning

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Psychiatry & Physician Aid in Dying[7]

- Physician Aid in Dying (PAD): involves a physician prescribing a lethal dose of medication to a terminally ill patient. At some later time, the patient administers the medicine(s) to self.
- PAD is not:
  - Euthanasia (which may connote mercy killings)
  - Physician assisted suicide (which may connote SMI)
  - Physician assisted death (may emphasize MD role)
  - Terminal sedation for the eminently dying
  - Withdrawing or withholding care

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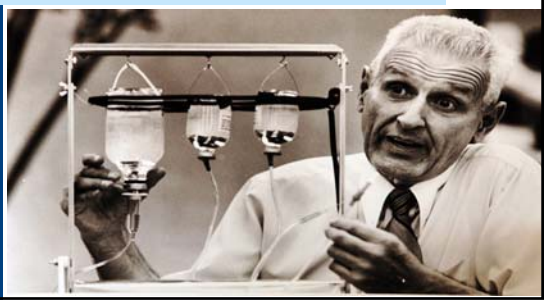
Dr. Death



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Psychiatry & Physician Aid in Dying[7]

- *So what does PAD have to do with psychiatry?*
- Most PAD laws require patients undergo psychological examination if there is question regarding the patient's judgment as impaired by any psychiatric or psychological disorder
- In Oregon from 1997 to 2013, 47 patients were referred for psychiatric examinations, while in 2014 of the 105 patients who requested PAD, only 3 were referred for psychiatric examination

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Psychiatry & Physician Aid in Dying[7]

- PAD has been legal in Oregon since 1997 and has not confirmed most fears about its abuse
  - Data from Oregon show that as of 2014, 1,327 people got prescriptions and interestingly only 859 used them
  - PAD accounted for 31 of every 10,000 deaths
  - Most of the patient's requesting PAD had cancer while the second most common diagnosis was ALS
  - The 3 most frequent reasons for requesting PAD were loss of autonomy, decreasing ability to participate in pleasurable activities and loss of dignity

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Psychiatry & Physician Aid in Dying[7]

- Currently PAD statutes: Oregon, Washington, Montana, Vermont. Most recently California (2015)
- Between 1998 to 2012 there has been increasing support of PAD by members of the general public…especially when the question is framed as:
- "Does a physician have the right to help patients end their lives by painless means?" *vs.*
- "Does a physician have the right to help patients commit suicide?"

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Death with Dignity

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Psychiatry & Physician Aid in Dying[7]

- AMA has a clear position that PAD is unethical
- AMA opinion 2.211 states *"Allowing physicians to participate in assisted suicide would cause more harm than good. Physician assisted suicide is fundamentally incompatible with the physician's role as healer, would be difficult or impossible to control and would pose serious suicidal risks."*
- A recent survey of members of the American Academy of Neurologists showed that most members felt that PAD is ethically permissible*

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Psychiatry & Physician Aid in Dying[7]

- As of 2016, the American Psychiatric Association (APA) does not have an official position statement about PAD
- Renee Binder, M.D. (former APA President)
- *"The discussion at the APA's September 2015 component meeting centered on whether APA should prepare a resource document to give guidance to members asked to do psychological evaluations of patient's requesting PAD."*

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Psychiatry & Physician Aid in Dying[7]

- For example it may address the following:
  - **What are the factors that need to be considered in doing such evaluations?**
  - **What are the criteria for competence?**
  - **If someone is depressed, especially in the context of having a terminal illness, can he/she still be competent to request PAD?**
  - **What are the ethical challenges to doing such evaluations?**
  - **Is only one psychological evaluation adequate?**
  - **Who should provide the oversight?**

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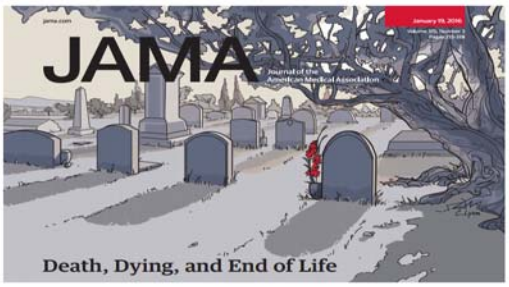
Death, Dying & End of Life



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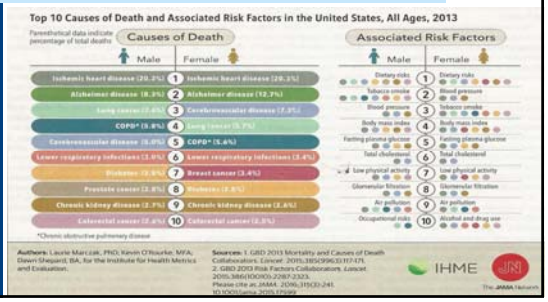
Death, Dying & End of Life[8]



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Death, Dying & End of Life[3]

- Singer et al. reported on the experience of 7,204 US adults older than 50 years who died between 1998 and 2010
- In their last year, 51% were troubled by moderate/severe pain, while 46-53% experienced at least a month of depression, periodic confusion, dyspnea and incontinence
- Medical care for the symptoms people experience at the end of life may be getting *worse not better* concluded the researchers

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Death, Dying & End of Life[3]

- 2014 Institute of Medicine published *Dying in America* which included an extensive review of the medical literature on the end of life
- Findings reported that when care is only narrowly focused on disease control without palliative care, patients experience more pain, more anxiety and more family exhaustion
- Overall, this results in more non-beneficial care, more hospitalizations and patients do NOT live longer, while at much higher costs

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End of Life Discussions[9]

- Hallmark paper by Wright et al. in *JAMA* Oct '08
- The objective was to determine whether end of life discussions with physicians were associated with fewer aggressive interventions whereby improving patient outcomes
- Main outcome measures included aggressive medical care and hospice in final week of life
- Secondary outcomes included patients' mental health and caregivers' bereavement adjustment

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End of Life Discussions[9]

- Hallmark paper by Wright et al. in *JAMA* Oct '08
- Results: Only 37% of patients reported remembering having end of life discussions with their physicians
- Such discussions were not associated with higher rates of major depression or worry
- However, such discussions were associated with lower rates of resuscitation, ventilation, ICU admission and earlier hospice enrollment

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End of Life Discussions[9]

- Hallmark paper by Wright et al. in *JAMA* Oct '08
- Results: More aggressive medical care was associated with worse patient quality of life and higher risk of major depression in bereaved caregivers
- While longer hospice stays were associated with better patient quality of life
- Better patient quality of life was associated with better caregiver quality of life at 6 mo follow-up

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End of Life Discussions[10]

- End of life discussions with a physician or other licensed caregiver are now being paid for by Medicare as of 2016
- For the first 30 minutes, Medicare will pay $86 in the office or $80 in a facility setting. In both settings, the caregiver would be paid $75 for an additional 30 minutes
- When provided as a separately payable service, advance care planning is subject to a 20% coinsurance as required by law

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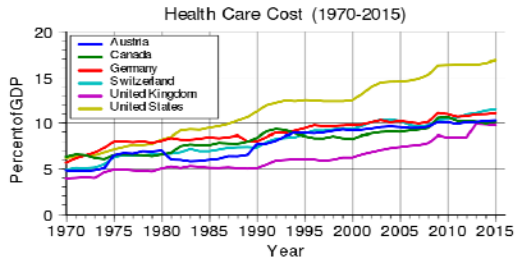
US Health Care Costs (% GDP)



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Health Care Costs at End of Life[11]

- As of 2016, 1 out of every 4 Medicare dollars is spent in the last 12 months of life
- 60% of spending during the last 6 months of life among Medicare beneficiaries occurs during their *final month of life!*
- US spending during the years-long decline to death from chronic disease is 4 times greater than the amount spent by wealthy European countries, but gives us no more life expectancy

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Health Care Costs at End of Life[12]

- Original investigation by Bekelman et al. in *JAMA* Jan 2016
- *"Comparison of Site of Death, Health Care Utilization and Hospital Expenditures for Patients Dying with Cancer in 7 Developed Countries"*
- Results: Hospital expenditures near the end of life were highest in US > Canada & Norway, intermediate in Germany and Belgium, while lowest in the Netherlands and England

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Health Care Costs at End of Life[12]

- Original investigation by Bekelman et al. in *JAMA* Jan 2016
- **Interestingly…**
- US had the lowest proportion of older patients dying in the hospital
- Only 22.5% of US decedent's > 65 years with cancer died in acute care hospitals
- Only 29.5% of US decedent's > 65 years with cancer died in acute care hospitals or skilled nursing facilities combined

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Health Care Costs at End of Life[12]

- Original investigation by Bekelman et al. in *JAMA* Jan 2016
- In fact, in 2010 death in the hospital was nearly half that of most other countries studied
- Note in the early 1980s more than 70% of US cancer patients died in the hospital
- Over the last 30-40 years in the US there has been much greater recognition of preferences for home-based end of life care

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Quality of Life at End of Life[13]

- Original investigation by Wright et al. in *JAMA* Jan 2016
- *"Family Perspectives on Aggressive Cancer Care Near the End of Life"*
- Objective: Family members perceptions of the quality of end of life care and patients' goal attainment
- Design: 1,146 family members of Medicare patients with advanced stage lung or colorectal cancer who died in 2011

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Quality of Life at End of Life[13]

- Original investigation by Wright et al. in *JAMA* Jan 2016
- Results: Of the 1,146 patients with cancer, bereaved family members reported excellent end of life care for 51.3%, very good for 27.8% and good/fair/poor for 20.9%
- Note 81.1% indicated that patients' end of life wishes were followed a "great deal," whereas 18.9% reported that end of life care was "somewhat/not at all" consistent with patients' wishes

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Quality of Life at End of Life[13]

- Original investigation by Wright et al. in *JAMA* Jan 2016
- Results: Only 56.7% of patients died in their preferred location
- Earlier hospice enrollment, avoidance of ICU admissions within 30 days of death and death occurring outside the hospital were all associated with perceptions of better end of life care
- These findings support advance care planning consistent with the preferences of patients

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End of Life Issues in Psychiatry

In conclusion…

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Necropolis

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Autopsia Cadaverum

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Voodoo Queen

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Old Sparky

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WAR

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End of Life Issues in Psychiatry

Everyone dies.

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End of Life Issues in Psychiatry

Death is not an inherent failure.

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End of Life Issues in Psychiatry

Neglect, however, is.

Atul Gawande, MD, MPH

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Dia de los Muertos

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End of Life Issues in Psychiatry

A good funeral is one that gets the dead where they need to go and the living where they need to be.

Thomas Lynch

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Although the world is full of suffering, it is also full of the overcoming of it.

Helen Keller

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Thank You

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