End of Life Care:

Caring for Patients With Advanced Illnesses:
_Palliative Medicine, Hospice, and Physician Aid-in-Dying_

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Objectives

- Understand the definitions of and differences between palliative care and hospice
- Describe the services that palliative medicine provides to patients with life-limiting illnesses
- Describe the services that hospice care provides to patients as well as the location(s) where hospice is provided
- Describe the eligibility criteria patients must meet to participate in physician aid-in-dying programs in select states
- Understand the differences between palliative medicine/hospice and physician aid-in-dying
- Anticipate areas of risk that may arise for physicians practicing in palliative medicine and hospice
Mr. Davidson (name changed)

- 58 year old gentleman with newly diagnosed lung cancer that has metastasized to his bones and liver
- Diagnosis was made after he came to the emergency room with unrelenting lower back pain and new pain in his abdomen
- He is married and has three children ages 25, 20, and 13
- He works as a high school English teacher and is deeply dedicated to his job
- Strong Catholic faith
- Would like to proceed with chemotherapy but is concerned about how he could ever go back to work with his current level of pain
- The oncology team recommends a palliative care consult

What is Palliative Medicine?

- Recognized by American Board of Medical Specialties in 2006
- Team-based approach to alleviation of suffering and promotion of quality of life when living with illness
- Physical, emotional, existential, spiritual pain
- Symptom management and advanced communication around goals and treatment preferences
- No intent to hasten or slow death: supportive of natural process
- Available to all patients regardless of their age, diagnosis, disease stage, or prognosis
- **Available to patients concurrently** with disease-directed therapy (chemotherapy, cardiac support devices, dialysis, etc.)
- **Mostly inpatient consultation**, emerging clinics, limited home-based palliative care
Indications for Palliative Medicine Consultation

- Management of symptoms related to disease or treatment (or both)
- Pain control
- Nausea/vomiting
- Shortness of breath
- Constipation/bowel obstruction
- **Goals of therapy conversations**
- Emotional/spiritual support
- Referrals to ethics committee

Symptoms Experienced in Advanced Illnesses
World Health Organization

“Palliative care is an approach that improves the quality of life of patients and their families facing the problem[s] 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 medicine...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 complications.”

Oncology & Palliative Medicine

- ASCO Statement: Toward Individualized Care for Patients with Advanced Cancer (Journal of Clinical Oncology, 28:1-6, 2011)
  - Individualized approach to discussing and providing disease-directed and supportive care throughout the continuum of care
  - Discussion of patient’s goals and preferences improves patient care
  - Oncologists should curtail the use of ineffective therapy and ensure a focus on palliative care
Who Provides Palliative Medicine?

- Interdisciplinary team: MD, RN/NP, Social Work, Chaplaincy
- Began mostly in inpatient setting with more recent migration to outpatient setting as well
- American Board of Medical Specialties designated Hospice & Palliative Medicine as a subspecialty in 2006
- 2 main foci: treatment of symptoms and advanced communication around goals of therapy
- Increasing number of fellowship-trained providers, though many have “grandfathered” into specialty

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Palliative Care Best Practices  (Kelley, AS et al, NEJM 2015: 373: 747-5)

<table>
<thead>
<tr>
<th>Domain</th>
<th>Key Recommendations</th>
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<tbody>
<tr>
<td>Structure and processes of care</td>
<td>Interdisciplinary team, comprehensive interdisciplinary assessment, education and training, relationship with hospice program</td>
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<tr>
<td>Physical aspects of care</td>
<td>Pain and other symptoms are managed with the use of best practices</td>
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<tr>
<td>Psychological and psychiatric aspects of care</td>
<td>Psychological and psychiatric issues are assessed and managed; grief and bereavement program is available to patients and families</td>
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<tr>
<td>Social aspects of care</td>
<td>Interdisciplinary social assessment with appropriate care plan; referral to appropriate services</td>
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<tr>
<td>Spiritual, religious, and existential aspects of care</td>
<td>Spiritual concerns are assessed and addressed; linkages to community and spiritual or religious resources are provided as appropriate</td>
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<tr>
<td>Cultural aspects of care</td>
<td>Culture-specific needs of patients and families are assessed and addressed; recruitment and hiring practices reflect the cultural diversity of the community</td>
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<tr>
<td>Care of the imminently dying patient</td>
<td>Signs and symptoms of impending death are recognized and communicated; hospice referral is recommended when patient is eligible</td>
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<td>Ethical and legal aspects of care</td>
<td>Patient’s goals, preferences, and choices form basis for plan of care; the team is knowledgeable about relevant federal and state statutes and regulations</td>
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* Adapted from the National Consensus Project for Quality Palliative Care.¹
Hospital-Based Palliative Consultations

- 125% increase between 2000-2008 (Center to Advance Palliative Care, 2010)

Mr. Davidson

- Palliative MD evaluated his symptoms and prescribed medications to address his cancer pain and bone pain and helped him complete an advanced directive
- He expressed many concerns about how his youngest child is taking the news and whether he would ever be able to return to work: “Teaching is my life”
- Social worker offered information on support groups for his teenager and chaplain began to discuss his fear that he couldn’t die “until [he] was right with God”
- Significant improvement in pain and anxiety, with plan to follow up with his pastor around his spiritual concerns and to take his son to a support group
- Followed up in palliative clinic when saw oncologist; medication adjustments made, continued support provided and relationship built
What is Hospice Care?

- Medicare Hospice Benefit created in 1982
- Type of palliative medicine for patients with a prognosis of <6 months as certified by 2 MDs
- Same interdisciplinary team as palliative medicine
- Generally provided in patients’ homes or nursing homes with few free-standing hospice facilities
- Generally not provided with concurrent therapy (e.g., palliative chemotherapy)
- Different levels of care on home hospice depending on patient’s needs:
  - Routine Home Care
  - Continuous Care
  - Respite Care
  - General Inpatient Care (GIP)
2014 Hospice Statistics

- Hospice at home: 41.7%; nursing home: 17.9%; residential facility: 7%
- Inpatient hospice: 26.4% (1/3 of hospices contract for beds in facilities)
- Acute care hospital: 7%
- **Median time on hospice (50th percentile): 18.5 days (2013)**
- 2010 → 2012: Percent of patient deaths while on hospice increased from 41.9% to 44.6%

Source: National Hospice and Palliative Care Organization 2014 Edition, *Hospice Care in America*

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**Important Facts to Know About Hospice**

- Pt can elect to stop hospice services if they desire
- Hospice and palliative medicine are NOT equivalent to “doing nothing” or “giving up”
- How we frame conversations about these options is critically important to the wellbeing of patients and families
- Knowing facts and myths about hospice and palliative medicine enables discussions about these options to be fully informed
- There are geographic and SES-related disparities in availability and quality of both hospice and palliative care
Summary of Palliative Medicine and Hospice

Table 1. Palliative Care as Compared with Hospice

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Palliative Care</th>
<th>Hospice</th>
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<tr>
<td>Model of care</td>
<td>Interdisciplinary team, including physicians, nurses, social workers, chaplains, and staff from other disciplines as needed; primary goal is improved quality of life</td>
<td>Interdisciplinary team, including physicians, nurses, social workers, chaplains, and volunteers, as dictated by statute; primary goals are improved quality of life and relief of suffering (physical, emotional, and spiritual)</td>
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<td>Eligibility</td>
<td>Patients of all ages and with any diagnosis or stage of illness; patients may continue all life-prolonging and disease-directed treatments</td>
<td>Patients of all ages who have a prognosis of survival of 6 mos. if the disease follows its usual course; patients must forgo Medicare coverage for curative and other treatments related to terminal illness</td>
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<td>Place</td>
<td>Hospitals (most common), hospital clinics, group practices, cancer centers, home care programs, or nursing homes</td>
<td>Home (most common), assisted-living facilities, nursing homes, residential hospice facilities, inpatient hospice units, or hospice-contracted inpatient beds</td>
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<td>Payment</td>
<td>Physician and nurse practitioner fees covered by Medicare Part B for inpatient or outpatient care; hospital teams are included within Medicare Part A or commercial insurance payments to hospices for care episodes; flexible bundled payments under Medicare Advantage, Managed Medicaid, ACOs, and other commercial payers</td>
<td>Medicare hospice benefit; standard hospice benefit from commercial payers is usually modeled after Medicare; Medicaid, although coverage varies by state; medication costs are included for illnesses related to the terminal illness</td>
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* ACO denotes accountable care organization.

Palliative Care Integrative Model

Palliative care is initiated when patients are diagnosed with any serious or advanced chronic illness. Ultimately, life-prolonging care is discontinued according to patient’s wishes or when the harm of treatment outweighs its benefits.

As illness progresses, the ratio of palliative care to life-prolonging care gradually increases.
Mr. Davidson

- Tolerated chemotherapy well with good control of disease and was able to return to work. Good control of pain and anxiety
- 9 months later, was hospitalized again for a severe pneumonia. Imaging studies demonstrated progression of disease in his other lung, growing masses in his liver, and metastases in his brain
- Cancer therapy deferred until infection resolved
- Palliative care team consulted and patient indicated he would not want to be placed on a ventilator or undergo resuscitation
- Continued to experience functional decline and lack of appetite
- Multiple discussions with pt and family → home hospice care
- Pt concerned about dying from massive seizure and inquired about physician aid-in-dying

Impact of Palliative Care Consultation

- Reduction in non-beneficial or lengthy ICU stays
- Discontinuation of costly interventions such as x-rays, mechanical ventilation, and blood transfusions
- Initiation of symptom-focused medications for pain, dyspnea, nausea, vomiting, depression, etc.
- Prevention of non-beneficial interventions that don’t align with patient goals
Physician Aid-in-Dying

- Physician Aid-in-Dying legal in increasing number of states
- Physicians do not have to participate (conscientious objection) and are also not obligated to make a referral to another provider
- Distinct from euthanasia, which is defined as a physician directly administering a lethal dose of a medication with the intention of ending a patient’s life
- In Aid-in-Dying, physician writes prescription but patient self-administers medication with intention to end their own life

Aid-in-Dying: The Oregon Experience

- Since the law was passed in 1997, a total of 1,327 people had prescriptions written and 859 people have died from ingesting medications prescribed
- Of the 105 DWDA deaths during 2014, most (67.6%) were aged 65 years or older. As in previous years, the patients were commonly white (95.2%) and well educated (47.6% had a least a baccalaureate degree)
- In 2014, 68.6% of patients had cancer, 16.2% had ALS, 3.8% had COPD, and 2.9% had heart failure
- Most (89.5%) patients died at home, and most (93.0%) were enrolled in hospice care either at the time the DWDA prescription was written or at the time of death
- As in previous years, the three most frequently mentioned end-of-life concerns were: loss of autonomy (91.4%), decreasing ability to participate in activities that made life enjoyable (86.7%), and loss of dignity (71.4%)
Aid-in-Dying Laws

- Require attending physician (usually MD who manages terminal disease, but can be primary care MD) to be willing to write prescription for patient
- Attending physician and consulting physician must evaluate patient:
  - To determine if they are eligible for the Act (state resident, >18 years of age, prognosis <6 months, + physical ability to self-administer medication, + decision making capacity)
  - To assess whether they require a mental health evaluation (**only required if MD has concern that mental illness is interfering with decision making capacity**; requires psychiatrist or PhD psychologist)
  - Patient must be counseled about the options of palliative medicine or hospice, and must also be reminded that they can change their minds about using the med

Aid-in-Dying Law Steps

- 2 requests by patient directly to attending physician, must be made 15 days apart and documented in writing
- Referral by attending physician to consulting physician, who fills out a written attestation as well
- Optional mental health evaluation
- Specific process for picking up medication from pharmacy
- Additional forms to be filled out prior to administration of medication
Mr. Davidson

- At the time, California did not have an aid-in-dying law
- He read about Oregon’s law and wondered if option would become available soon in California
- Reasoning included that he would not want to be “lying in bed doing nothing” if his brain metastases worsened or caused him a seizure
- Feared uncontrolled pain
- Discussed role of faith and family in addressing his fear
- Was receptive to discussing what the end of his life may look like and how specifically the hospice team could help

Impact of End of Life Care in Oregon vs Washington vs rest of USA
## Potential Risks for Providers of Hospice and Palliative Medicine

- **Medical management:**
  - Proper training in how to titrate medications (opiates in particular) to achieve comfort without expediting dying process
  - Going through any necessary training to be able to prescribe aid-in-dying medication

- **Communication issues:**
  - Consent/informed decision making
  - Conflict between patient/family or intra-family conflict around decision making
  - Language barriers and cultural issues during difficult conversations

- **Documentation and Teamwork:**
  - Minimal or unclear documentation of discussion around goals of care and clinical decision making (particularly around titration of comfort medications)
  - Inconsistent oversight of team members (nursing, social work) leading to poor outcome for patient/family

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## Mr. Davidson

- Palliative team had a long discussion with him about his plan of care prior to discharge from hospital
- His goals included being pain free for as long as possible and being able to remain functional and engaged in life
- To this end, opted for radiation therapy to manage his brain metastases but deferred other forms of therapy, and felt well enough to attend these sessions
- Weekly family meetings and individual sessions with hospice SW and his own pastor
- Remained lucid enough to enjoy visits from his students though grew increasingly weak
- Died in his sleep, with pain and anxiety well controlled in the two months he was on hospice care
Palliative medicine is a growing field that is rapidly becoming included in comprehensive care of patients with advanced illnesses

- Focuses on quality of life through symptom management and discussions of patient goals and values
- Available mostly in hospital setting but increasingly in outpatient clinics, limited number of home based palliative care programs

- Hospice is a type of palliative medicine for patients with a prognosis of <6 months and is usually provided in patient home or nursing home

- Physician Aid-in-Dying is now available in multiple states and requires attending physicians and patients to go through a clear process outlined in the law to certify that a patient qualifies for this option

- Areas of potential risk may arise in realms of communication, medical management, documentation and team management

Take-Home Points

Thank you!

- Please feel free to be in touch with questions:

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