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Equitable Care at End of Life

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This educational activity is being presented without bias or conflict of interest by the planners and presenter.

Disclosure of Service

I am Chair of the Hospice and Palliative Medicine LKA Approval Committee at the American Board of Internal Medicine (ABIM).

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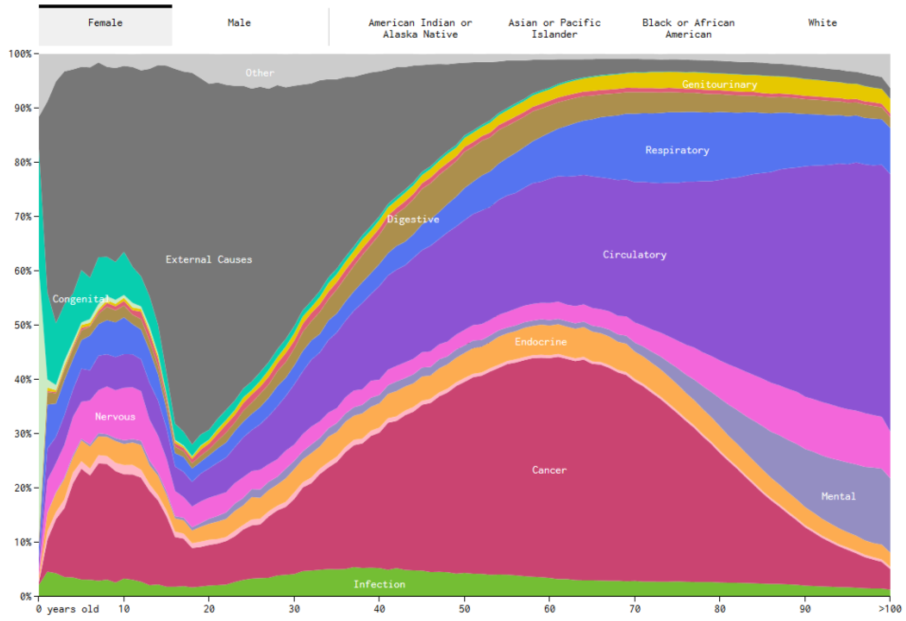
As Chair of the Approval Committee, I agree to keep exam information confidential.

As is true for any ABIM candidate who has taken an exam for certification, I have signed the Pledge of Honesty in which I have agreed to keep ABIM exam content confidential.

No exam questions will be disclosed in my presentation.



OBJECTIVES:

- Discuss specialty and generalist level palliative care – what, why, and how.
- Explore ways to create an environment in which equitable care is provided to all at end of life
- Describe the disparities in the management of pain and other symptoms in rural and underserved communities
- Discuss the barriers that may interfere with access to care and pain and symptom management for both the patient and provider
- Discuss evidence-based approaches to facilitate access to care for our patients

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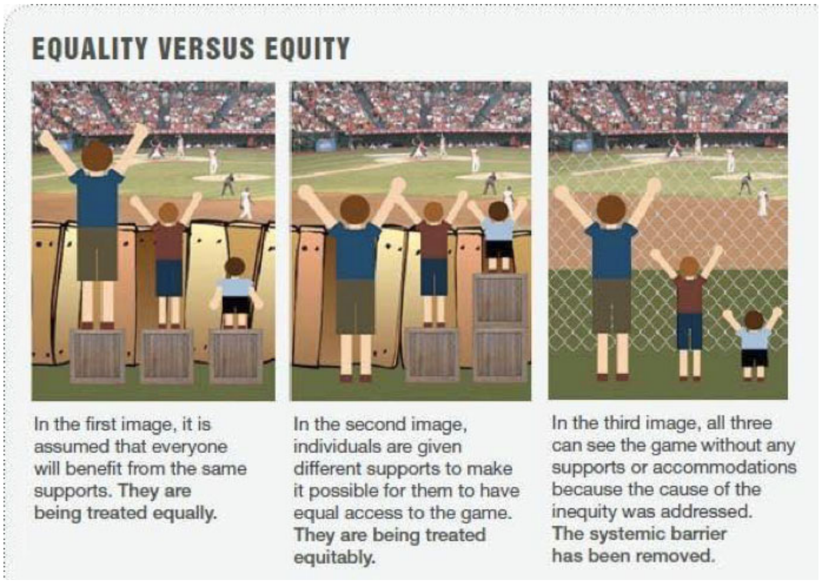

EQUALITY VERSUS EQUITY

In the first image, it is assumed that everyone will benefit from the same supports. They are being treated equally.

In the second image, individuals are given different supports to make it possible for them to have equal access to the game. They are being treated equitably.

In the third image, all three can see the game without any supports or accommodations because the cause of the inequity was addressed. The systemic barrier has been removed.

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Mr. G

Mr G is a 77 yo Hispanic male who is brought to your clinic by his son, Gabriel.

Gabriel has brought his father up from rural Mexico given concerns around his health and lack of access to effective medical care.

Mr. G has suffered a 15 lb weight loss over the past 3 months with complaints of nausea and pain after eating. He is more bloated and distended despite taking very minimal nutrition.

Mr. G

Mr. G appears chronically ill with pale conjunctiva and nail beds. His BP is somewhat low at 108/68 with a pulse of 90.

Examination of the lungs reveals dull bases bilaterally and his abdomen is tender without guarding and distended with shifting dullness and a slightly protuberant umbilicus.

Labs show anemia and elevated liver enzymes with an albumin of 2.8.

CT reveals a mass in the tail of the pancreas with ascites, multiple lesions in the liver and lungs.

Gabriel says “do not tell my dad anything, talk only with me!”

National Consensus Project

The NCP *Clinical Practice Guidelines for Quality Palliative Care,* *Fourth Edition* creates a blueprint for excellence by establishing a comprehensive foundation for gold-standard palliative care for all people living with serious illness, regardless of their diagnosis, prognosis, age or setting

https://www.nationalcoalitionhpc.org/ncp/

A Tiered Approach to Integration of Palliative Care Support

Specialty Palliative Care

"Champion" Generalist Palliative Care

Generalist Palliative Care

Palliative Care Practice Guidelines

The guidelines describe core precepts and structures of clinical palliative care programs divided into eight dedicated sections:

- **Structure and Processes of Care**
- **Physical Aspects of Care**
- **Psychological and Psychiatric Aspects of Care**
- **Social Aspects of Care**
- **Spiritual, Religious and Existential Aspects of Care**
- **Cultural Aspects of Care**
- **Care of the Patient Nearing the End of Life**
- **Ethical and Legal Aspects of Care**

DOMAIN 6: Cultural Aspects of Care

Guideline 6.1 Global

The IDT delivers care that **respects patient and family cultural beliefs, values, traditional practices, language, and communication preferences** and builds upon the unique strengths of the patient and family.

Members of the IDT works to increase **awareness of their own biases** and seeks opportunities to learn about the provision of culturally sensitive care . The care team ensures that its environment, policies, procedures, and practices are culturally respectful.

Criteria – Cultural Aspects (excerpt)

Criteria: 6 .1 .1

The IDT asks the patient or surrogate to **identify and define family**, which may include members of the family of origin, as well as the patient's family of choice .

6 .1 .2

IDT members recognize that the provision of quality palliative care requires an understanding of the **patient's and family's culture and how it relates to their decision-making process, and their approach to illness, pain, psychological, social, and spiritual factors, grief, dying, death, and bereavement.**

6 .1 .3

The IDT understands that each person's self-identified culture includes the intersections of race, ethnicity, gender identity and expression, sexual orientation, immigration and refugee status, social class, religion, spirituality, physical appearance, and abilities .

6 .1 .4

The IDT recognizes that patients and families may have experienced barriers to receiving culturally respectful health care, and that these prior experiences may result in mistrust of the health care system .

6 .1 .5

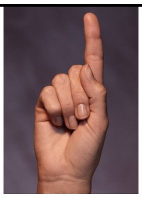
The IDT commits to continuously practice **cultural humility and celebrate diversity**.

6 .1 .6

In delivering culturally sensitive care, the IDT regularly **participates in trainings to increase cross-cultural knowledge, empathy, and humility**. The IDT focuses on building and practicing these skills to avoid imposing personal values, beliefs, and biases on the patient and family The IDT also recognizes that culture is a strength that patients and family members bring to their plan of care .

For your patient….

- We cannot use retrospective population data to predict for the individual patient.
- Don't Assume
- Ask, engage
- Be Curious to understand.
- Your approach is intrinsically part of the treatment



What must happen first?

“How much information do you find helpful?…”

Cultural and ethnic assessment:

- how does this family prefer to make healthcare decisions?,
- how will information be shared, how much, and with whom?

Good communication skill requirements are <u>universal</u> for clinicians:

1. Establish the setting – privacy, respectful
2. Facilitate rapport - **sit down**
3. **Use a professional interpreter or a language-line**
4. Open ended questions

“Bad News”
“Serious News”

- “any information that adversely alters one’s expectations for the future”
- Has a lasting effect on the patient and family – associated with strong emotions – thus strong memories
- Surgeons, Oncologists, and Critical Care physicians most frequently deliver serious news
- Clinicians tend to avoid these conversations and express discomfort

Stop talking….

- Don’t just do something, sit there
- Avoid blanket reassurances

Communicating Serious News

- Most patients want as much information as possible.
- Prefer “bad news” delivered in a positive manner.
- Prefer qualitative not quantitative estimates.
- The further advanced the disease, fewer patients want to have explicit conversations around their prognosis.

Hagerty RG, Butow PN, Ellis PA, Lobb EA, Pendlebury S, Leighl N, Goldstein D, Lo SK, Tattersall MH: Cancer patient preferences for communication of prognosis in the metastatic setting. J Clin Oncol 2004;22:1721–1730.

Mager WM, Andrykowski MA: Communication in the cancer ‘bad news’ consultation: Patient perceptions and psychological adjustment. Psychooncology 2002;11:35–46.

Cultural Competence & Humility

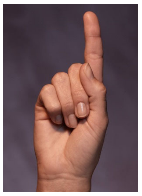
- Culture (shared beliefs) provides a framework of expectations concerning communication with:
  - – health professionals,
  - – family members and patients,
- Culture impacts the dynamics of decision making and the dying process.
- Cultural competence (humility) recognizes that serious illness practices and attitudes are influenced by context, and that **everyone** brings their own cultural context to an encounter (including the healthcare personnel).

Family-Centered vs. Patient-Centered

- In many cultures, family members are expected to make decisions for their loved one, rather than the patient exerting autonomy by choosing for themselves.
- In cultures in which full disclosure is not the norm, patients are less likely to make medical decisions.
- In many cultures, the physician is expected to take a more directive role and provide opinions and specific recommendations.
- Yet *do not assume, ASK!*

Language Barriers

- Best practice is to **<u>always</u>** use a professional interpreter or language line when consenting a patient or delivering serious news!
- Do not use family unless the patient has given this directive and even then, **not** for serious news.
- Interpreters can be literal or cultural
  - Literal – say what's said
  - Cultural – identify what cannot be said or how to say what needs to be said.



What are the FIRST questions asked?

- How do you prefer to make decisions around your healthcare?
- How much information and detail are you comfortable with me sharing with you? With your family?
- Is there anyone who you want to have with you when discussing your treatments or results?
- Who would you like to make healthcare decisions for you?
  - *Now? or*
  - *When you are unable to do so for yourself?*

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Mr. G

Mr. G confirmed through the interpreter that he preferred NOT to hear anything regarding his condition

He instructed us to speak with his son, Gabriel and not to whisper outside his hearing!

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Physical Aspects of Care: Symptom Management

The palliative care interdisciplinary team (IDT) endeavors to relieve suffering and improve quality of life, as defined by the patient and family, through the safe and timely reduction of the physical symptoms and functional impairment associated with serious illness.

Physical Aspects of Care (excerpt)

Criteria:

2 .1 .1

The goal of symptom management is to **improve physical well-being, functionality, and quality of life** to a level acceptable to the patient, or to the health care surrogate if the patient is unable to report distress.

2 .1 .2

The symptoms associated with serious illness and treatments are anticipated and prevented.

2 .1 .3

The IDT recognizes that culture can influence the approach to illness, reporting of symptoms, preferences around treatment and decision-making process.

2 .1 .4

Effective symptom management requires attention to the physical, emotional, spiritual, and cultural factors, as well as the social determinants of health that contribute to the total pain and suffering associated with serious illness.

Effective Symptom Management

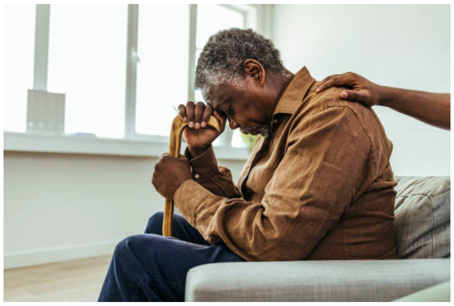
- Health disparities are pervasive at EOL – particularly in NH
- Racial/ethnic minorities are less likely to complete ACP
- Black patients were less likely to use hospice care
- Black and Hispanic patients were more likely to experience EOL hospitalizations

…and social determinants

- Racial and ethnic minority residents more likely to experience poor pain and symptom management
- The opioid epidemic has particularly impacted rural communities and the African-American population
- Access to opioids and symptom management medications is less in marginalized communities
- Where you live directly influences life-expectancy

…social determinants

- Prior Authorizations delay timely access to prescriptions and treatments
- Pharmacies may limit or not stock needed medications
- Anxiety regarding addiction for the patient and caregivers can influence adherence



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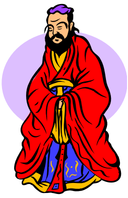
Prognosis



prog·no·sis (prg-nss) *n. pl.* **prog·no·ses** (-s)

a. A prediction of the probable course and outcome of a disease.

b. The likelihood of recovery from a disease.

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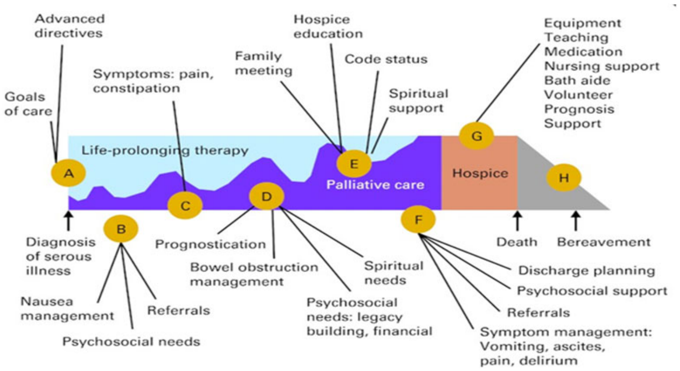
The Integration of Palliative Care in the entire trajectory of serious illness….



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"There's no easy way I can tell you this, so I'm sending you to someone who can."

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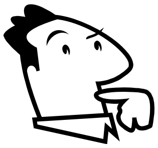
Prognosis

- Provides framework to make informed decisions about care
- Provides life-care planning
    - spiritual
    - financial
    - psychosocial – relationships/forgiveness
    - opportunity to say goodbye
    - life closure and legacy giving
- And not everyone wants to discuss this



Prognosis → Overestimate

- 326 patients with cancer in 5 Chicago hospices
- 20% accuracy in predicting prognosis
- 63% overestimate, 17% underestimate
- Only 37% would give frank disclosure, even when patient requested survival estimate
- Average survival time was 26 days; average communicated survival time was 90 days
- **Closer the relationship – more likely to err**
    - Christakis, Annals of Int Med, 2001

Prognostication – Hospital PC teams

4 Categories

- <3 days
- < 1 month
- 1-6 months
- > 6 months

Correct category - 58% accurate

85% accurate if prognosis 0-3 days

27% overestimate, 16% underestimate

48% cancer N = 429 patients

Fromme et al, JPM Dec 2010

Prognostication

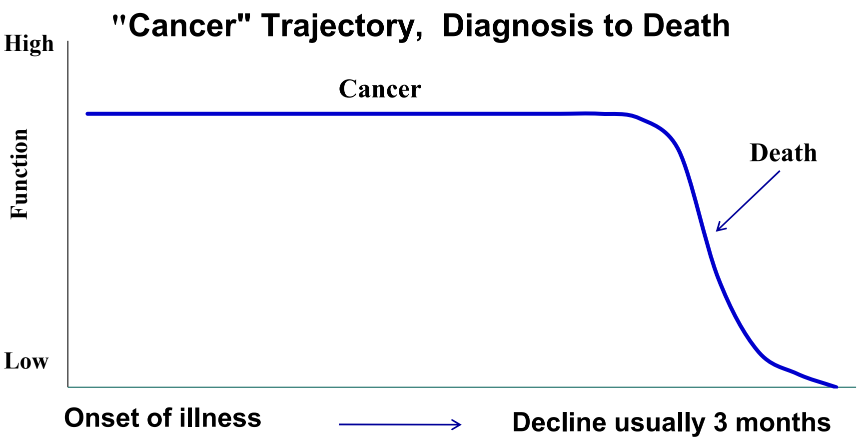
Would you be surprised if your patient died within the next year?

Lynn, 2005

Trajectory - Cancer

- Accounts for 30% of all deaths
- Highly functional early on with slow steady decline 3 months prior to death
- Dependence:
  - ○ 1 year prior to death - .77 ADL
  - ○ 3 months prior to death - 4.09 ADL

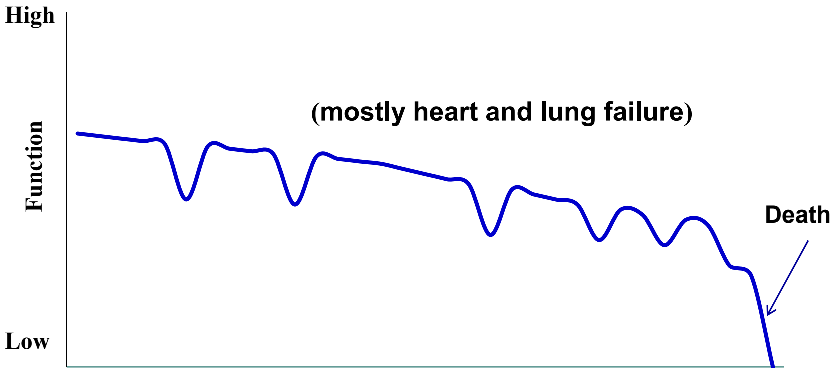
Disease Trajectories - Cancer



Trajectory - Organ Failure

- Account for 40% of all deaths
- Multiple exacerbations, often frequent hospitalizations
- Generally die during exacerbations but often “suddenly”
- Renal, liver, cardiac, pulmonary
- Functional status fluctuates with overall slow decline
  - ○ 1 year prior to death – 2.1 ADL
  - ○ 3 months prior to death – 3.66 ADL

Organ System Failure Trajectory



Multiple hospitalizations → **Death usually follows disease exacerbation**

Time frame – usually 2-5 years

Trajectory - Frailty

- Accounts for 20-30% of all deaths
- Most often = elderly women with multiple co-morbidities (not exclusively)
- Dementia often present
- Very slow rate of decline, with early functional decline
    - ○ 1 year prior to death – 2.92 ADL
    - ○ 1 month prior to death – 5.84 ADL

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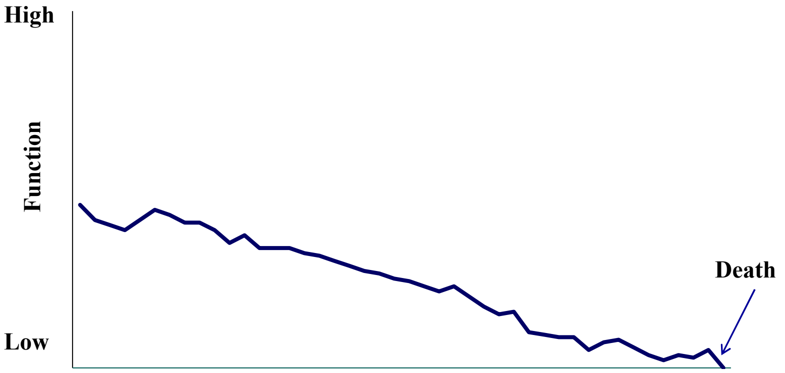
Frailty / Dementia Trajectory



High dependence on ADLs early in disease course → **Slow decline**

Time frame- usually 6-8 years

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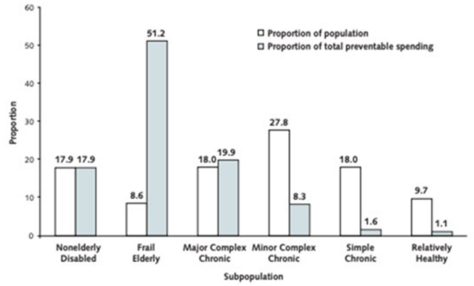
Proportion of population vs proportion of total preventable spend



Data were generated from Medicare administrative claims from 2012. The number of beneficiaries in this sample is 6 112 450.

8.6% of the ~6M population were frail elderly. They accounted for 51% of the total preventable spend.

Prognosis

- Important factors to consider
- Primary diagnosis
- Co-morbid illnesses
- Rate of decline
- Nutritional status
- Functional status
- Cognitive status
- Age and gender
- Number of hospitalizations in past year
- Will to live
- Other (psychosocial, emotional and spiritual)

Prognostication Data points

- Disease Specific Tools (ECOG, FAST, MELD, NYHA)
- Data points: Albumin, Cr cl, BNP, CO2
- BMI/weight
- ADL impairments
- MMSE/MiniCog
- PPS/Karnofsky
- Add in =
- Rate of decline
- Co-morbidities
- Secondary conditions

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Prognosis

- **Co-morbidities** – associated conditions not related to the primary illness whose presence adds to the burden of illness and prognosis
  - ○ Dementia patient – cardiac disease, pulmonary, anemia.
- **Secondary conditions** – conditions directly related and often a result of the primary diagnosis
  - ○ Dementia patient – delirium, dysphagia, pressure ulcers

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Prognostic Tools - Advanced Diseases

- Prognostat – age, gender, diagnosis, PPS http://web.his.uvic.ca/Research/NET/tools/PrognosticTools/PalliativePerformanceScale/Prognostat/ToEstimateSurvivalOfYourPatient/index.php
- ePrognosis.org JAMA 2012
- MRI, ADEPT for advanced Dementia
- Palliative Prognostic Score (PaP) – FF #124
  - KS, WBC, lymphocytes, clinical, anorexia, dyspnea
- Palliative Prognostic Index (PPI)
  - PPS, edema, oral intake, dyspnea, delirium in cancer patients

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Depression and Social Isolation

- Increased rates of hospitalization
- Increased mortality post MI
- Increased mortality from cancer
- Overall higher mortality rates from all diseases
- Lower immune functions
- Depression and social isolation are independent risk factors

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Spiritual Beliefs and Prognosis

- Major source of coping
    - 85% hospitalized pts
    - 40% most important factor
- Multiple studies in chronic diseases demonstrate source of coping
- Suggested role in improving depression
- Literature demonstrates beneficial effects on health outcomes
- May be associated with a more aggressive approach at end of life (“the miracle”)

Domain 7: Care of the Patient Nearing the End of Life

Guideline 7.1
Interdisciplinary Team

- The IDT includes professionals with training in end-of-life care, including assessment and management of symptoms, communicating with patients and families about signs and symptoms of approaching death, transitions of care, and grief and bereavement.
- The IDT has established structures and processes to ensure appropriate care for patients and families when the end of life is imminent

History of Hospice Care in the US

- Hospice entered the US through the Connecticut Hospice project about 1971 (Florence Wald)
  - their project rapidly morphed towards a home-based model
- Medicare Pilot in 1982 – Medicare Benefit in 1986
- Home Care Benefit in the US as opposed to inpatient care like the UK
- Commercial Insurance integrated hospice care in the 1990’s

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Medicare Hospice Benefit (MHB)

- Hospice is a philosophy and model of care
- Medicare is a Federally regulated Insurance plan
- MHB is regulated by the Conditions of Participation (COPs) 42CFR418.1
  - **Mandates that care is provided by an interdisciplinary team.**
  - **Mandates a percentage of care is provided by trained Hospice Volunteers – 5% of total patient care hours**
- Hospice Medical Director role in medical oversight, compliance and quality – responsible for re-certifications
- Two 90 day periods and now unlimited 60 day periods if the patient remains eligible.
- Most commercial insurance mimics the MHB.

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Code of Federal Regulations

A point in time eCFR system

Displaying title 42, up to date as of 11/03/2022. Title 42 was last amended 11/03/2022. view historical versions

View table of contents for this page

PART 418 - HOSPICE CARE

Authority: 42 U.S.C. 1302 and 1395hh.

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Eligibility requirements § 418.20

“Entitled to Part A of Medicare; and

“Certified as being terminally ill in accordance with § 418.22”

“The certification must specify that the individual’s prognosis is for a life expectancy of 6 months or less if the terminal illness runs its normal course.” § 418.22(b)(1)

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Duration of hospice care coverage – Election Periods § 418.21

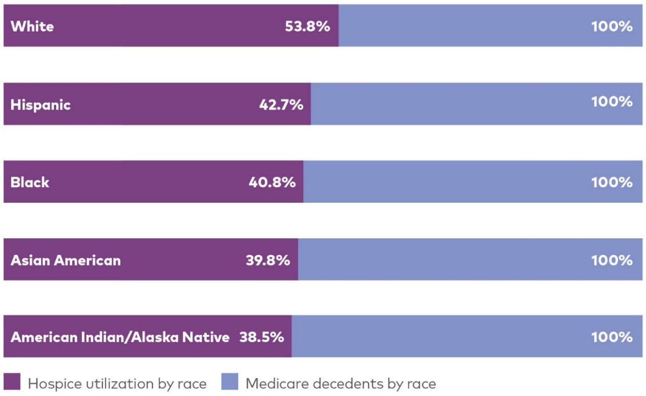
a) May elect to receive care during one or more of the following election periods:

   1) An initial 90-day period;
   2) A subsequent 90-day period;
   3) An unlimited number of subsequent 60-day periods.

b) “The periods are available in the order listed and may be elected separately at different times.”

c) File a NOE – Notice of Election

Figure 7: % of Medicare decedents by race who used hospice



Source: MedPAC March 2021 Report to Congress, Table 11-2

Note: *In previous years, the NHPCO Facts and Figures has presented data on the share of Medicare beneficiaries who used hospice by race. In an effort to focus on equity, we are now presenting data from the 2019 MedPAC March report to Congress, Table 11-2, focused on the percentage of Medicare decedents by race who used hospice.*

Barriers to Access

- knowledge regarding palliative and hospice care;
- healthcare literacy;
- communication with providers and family;
- perceived or experienced discrimination with healthcare systems;
- mistrust in healthcare providers;
- health care coverage,
- religious-related activities and beliefs on palliative and hospice care utilization and
- completion of advance directives among non-Hispanic Blacks.

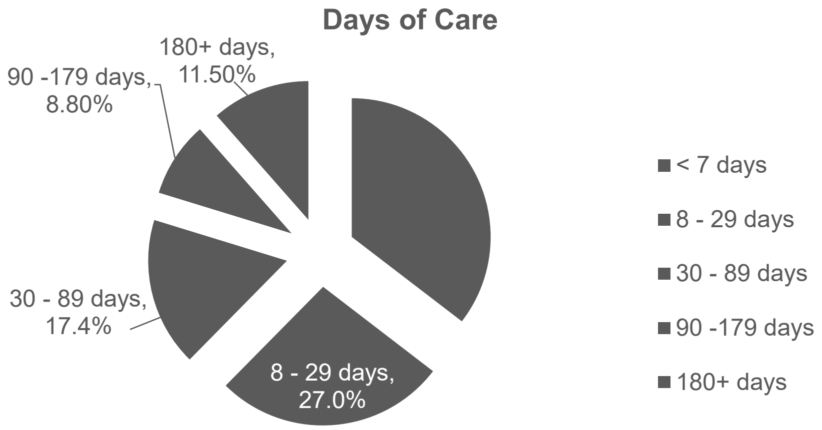
Lead the conversation with what it provides, not what it's called…

- Medicare has two home care benefits – a shorter one for rehab, a longer one to provide more support for the seriously ill people and their families
- Difference is one provides…
  - visits based on needs vs protocol
  - After hours/weekend visit availability/24-7 on call
  - Provision of equipment including oxygen
  - Provision of medications with home-delivery
- And I think you and your family would benefit from more robust support
- "Its called hospice care, have you had experience with this type of care?"

Correcting Myths and Misinformation

- We do not “*make someone hospice*”
  - They **elect** their hospice insurance benefit if they have one
- People can go in and out of hospice care – either be discharged or revoke their benefit.
- If they revoke or are discharged during a benefit period, they do lose the remaining days in that benefit period.
- Hospice is not limited to 6 months

Proportion of Patients by Length of Service - 2012

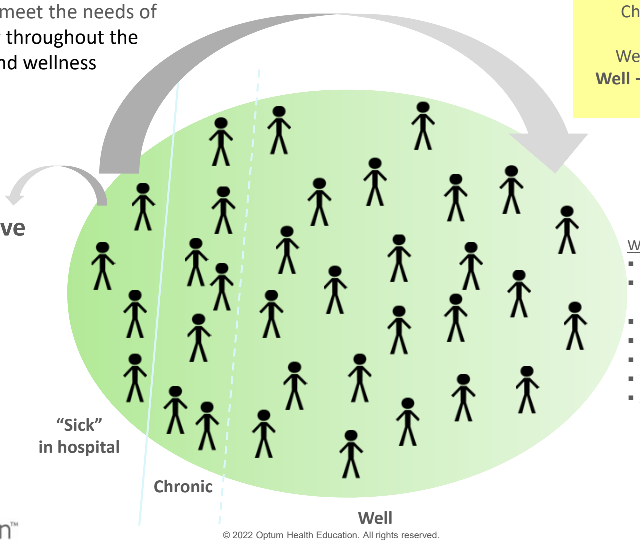


Source: NHPCO Facts and Figures, October 2013

Integrated System of Care | Population Based Health

The services and partnerships established in an integrated system of care meet the needs of the community throughout the entire health and wellness continuum.

Manage Populations
Well = keep them well
Chronic = manage conditions
Well → Sick → Well
Well → Sick → Palliative Care



Palliative Care

"Sick" in hospital

Chronic

Well

Wellness Services:
- Wellness Center
- Diet and Nutrition Coaching
- Mammography
- Colonoscopy
- Psychiatry / Psychology
- Women's Center
- Senior Center

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Caregiving Increases Mortality

Nurses Health Study: *prospective study of 54,412 nurses*
Increased risk of MI or cardiac death: RR 1.8 if caregiving >9 hrs/wk for ill spouse

Lee et al. Am J Prev Med 2003;24:113

Population based cohort study 400 in-home caregivers + 400 controls
Increased risk of death: RR 1.6 among caregivers reporting emotional strain

Schulz et al. JAMA 1999;282:2215.

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What about the symptoms of the family members?

Anxiety, intermittent anger & fear, mood lability, anorexia, fatigue.

Grief – deep mental anguish, deep or intense suffering.

- Does not begin exclusively at bereavement – but can begin in anticipation of real or potential loss.

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Available data that suggests that chronic bereavement and depression have similar immune and psychological effects, with women and Caucasians potentially being more vulnerable.

These studies support increased attention to caregiver burden and the potential chronic bereavement and depression in caregiver populations

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Family Support

- Most Families benefit from explanations as to what is happening in the dying process
    - Particularly agonal breathing or delirium when it occurs
- Families who know what to expect demonstrate less stress with the process
- Books and pamphlets can be helpful
- Bereavement support can decrease the likelihood of complicated grief reactions

As Expected Death Approaches

- Revisit goals of care and patient/family preferences
- Review signs, events of dying process to the degree that family wishes to hear. "*What you will see is…*"
- Personal, cultural, religious, rituals, funeral planning. Again, **in some cultures, it is inappropriate to "plan" while the patient is alive**.

Relief of Symptoms

- Use medications and non-medicinal interventions
- Titrate interventions to the level of distress – goal is relief, not to overpower or overdo.
- “To neither hasten nor prolong” – hospice motto
- The “**morphine drip**” **must have a specific indication** and titration must be guided and thoughtful to the relief of specifically defined symptoms such as dyspnea (not tachypnea alone) and pain. **When there is no symptom to relieve, there is no indication for continuous morphine**.

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After death occurs . . .

- Care shifts from patient to family and caregivers
- Different loss for everyone
- Be mindful and ask about rituals and observances
- Encourage family to take the time they need

Moving the Body

- Prepare the body – be mindful of rituals and cultural/religious practices
- Choice of funeral service providers
- Wrapping, moving the body
    - family presence
    - intolerance of closed body bags

Bereavement Care

- Healthcare Team's attendance at the visitation or funeral
- Letters of condolence – "*what I will remember*…"
- Facilitating follow up to assess grief reactions, provide support
- Assistance with practical matters – the death certificate

Loss, grief for all those who care….

- Repeated loss can impact professional caregivers
- Studies demonstrate that those in Oncology, in particular, are highly vulnerable
- Frequent losses can impact
    - function / control / independence
    - image of self / sense of dignity
    - relationships
    - sense of future

- **Mindfulness** work by professionals has been shown to be effective in addressing compassion fatigue and mitigating burn-out.

Conclusions

- Everyone writes their own story – who they are, how they have lived, what they value very much impacts how they die. This is the true meaning of dying with integrity or dignity.
- Cultural competency/humility is critical to good care
- Support and education for the family – care does not stop when direct “treatment” for the disease is no longer helpful.
- How we communicate with the patient and family has significant impact on their well-being.
- Symptom management is vitally important and complex in patients near the end of life. We have LOTS to Do!
- We, as healthcare professionals, are affected by the death of our patients and must pay attention to our own bereavement needs.

Reflections…

Thank you!

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