

Palliative Care Population Health Clerkship 2018

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What Is Palliative Care?

- Specialized medical care for people with serious illness focused on providing relief from symptoms and stress to improve quality of life for the patient and their support system (Get Palliative Care, 2018)



Figure 1. Picture of Dr. B.J. Miller, MD with patient Bruce. From the Netflix Documentary "End Game" (2018). Retrieved from <https://www.lifemattersmedia.org/2018/05/end-game-is-the-documentary-film-america-needs/>

<h2 style="text-align: center;">Palliative Care Criteria</h2>	<h2 style="text-align: center;">Hospice Criteria</h2>
<ul style="list-style-type: none"> ● Serious or life-threatening illness 	<ul style="list-style-type: none"> ● Terminal illness with prognosis of six months or less, if the disease runs its normal course
<ul style="list-style-type: none"> ● Encompasses patients of all ages, diagnostic categories, living with a persistent or recurring medical condition that adversely affects their daily functioning or will reduce life expectancy 	<ul style="list-style-type: none"> ● Certified by a physician or hospice physician
<ul style="list-style-type: none"> ● Patients can have palliative care while also having disease-directed therapies 	<ul style="list-style-type: none"> ● Receive care focusing on comfort and quality of life rather than curative
<ul style="list-style-type: none"> ● Covered under insurances by specialty symptom management 	<ul style="list-style-type: none"> ● Covered under Medicare Part A, Medicaid, or commercial insurance

Who should receive Palliative Care?

- Patients who are experiencing potential life-threatening or life-limiting conditions
 - Cancer, acute/advanced organ failure, progressive neurological illness, multimorbidity with poor prognosis
- Patients with complex medical courses
 - Symptom assessment and management
 - Medical decision-making
 - Goal-setting for end-of-life planning
 - Navigating clinician, family, and patient's wants
 - Disposition planning

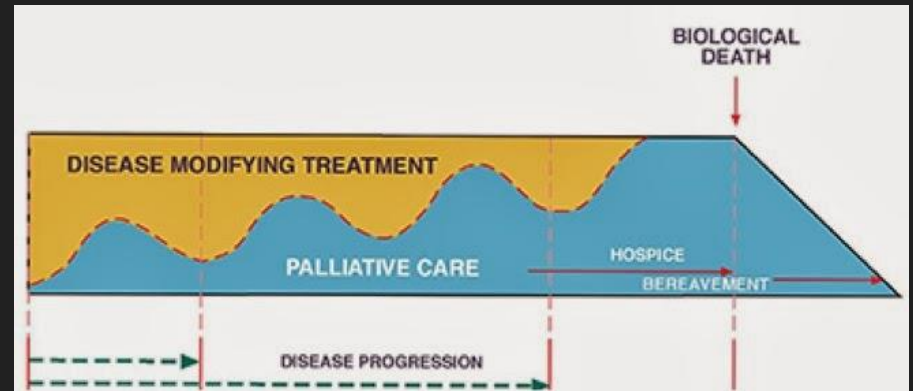


Figure 2: Palliative Care Continuum, Morrison (2004). From <https://www.nejm.org/doi/full/10.1056/NEJMra1404684>

Who benefits from Palliative Care?

- Patients, family members, and care providers
- Key demographics:
 - Any age, gender, sexual orientation, ethnicity, or religion
- Barriers to care:
 - Limited Workforce
 - Limited Research
 - Payment models

World Health Organization (2012). Retrieved from <http://www.thewhpc.org/resources/global-atlas-on-end-of-life-care>

Benefits of Adding Palliative Care Services to Metastatic Cancer Care:

- **Improved:**
 - Overall survival in NSCLC= 2.6 months (11.6 months vs. 8.9 months, $P=0.02$).
 - Depressive symptoms (16% vs. 38%, $P=0.01$) in NSCLC
 - Quality of Life
 - Patient satisfaction
 - Pain scores
 - Decreased utilization of Aggressive End of life Care

Temel JS et al. Early Palliative Care for Patients with Metastatic Non-Small Cell Lung Cancer. N Engl J Med. 2010. 363(8):733-42

National & State Hospital Trends

- US
 - 90% of US hospitals with 300+ beds report the presence of a palliative care program
 - 56% of hospitals with fewer than 300 beds (CAPC, 2016)
- Massachusetts
 - 92% (12/13) of MA hospitals with 300+ beds report the presence of palliative care
 - 80% (4/5) of MA hospitals with 50 beds or less (CAPC, 2016)

Disparities in Quality of Palliative Care

- Compared to other areas of health care, research in disparities in palliative care is limited.
- Studies document lower quality palliative care amongst minorities in several domains:
 - Satisfaction (Welch, 2005)
 - Communication (Smith, 2007)
 - pain management (Anderson, 2009)
 - Financial hardships (Welch, 2005)
- In addition, compared to Whites, minorities are more likely to die in the hospital and to receive intensive aggressive care in the last 6 months of their life (Hanchate, 2009).

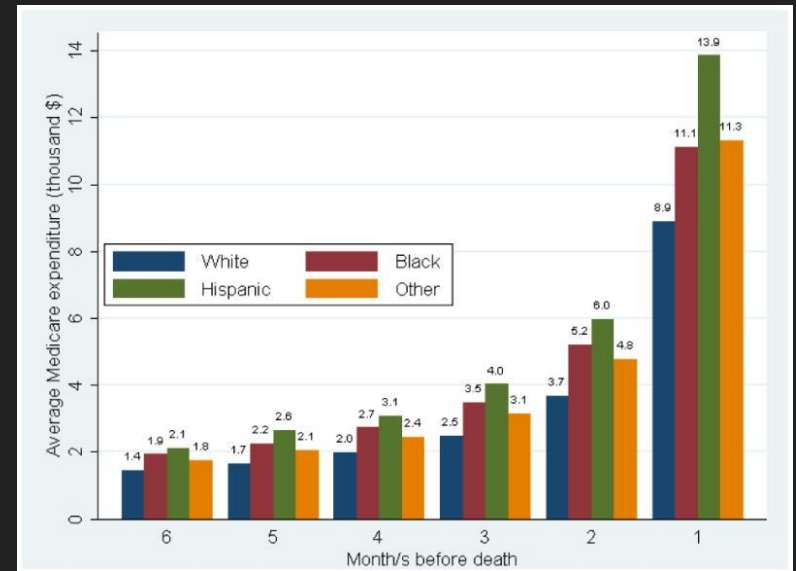


Figure 4: 30-Day Medicare expenditures for 2001 decedents, by months before death. Hanchate (2009). Adapted from <https://www.ncbi.nlm.nih.gov.ezproxy.umassmed.edu/pmc/articles/PMC3621787/>

All terminally ill patients, initial interview (n = 803)	African American (n = 115)	White (n = 688)	P value
Quality of patient-physician relationship measures*			
Patient has complete trust in the physician (61)†			
Strongly agree	77.9	84.4	0.31
Somewhat agree	18.6	10.8	
Disagree	3.5	4.8	
Physician respects the patient as an individual (81)†			
Strongly agree	77.2	91.1	<0.001
Somewhat agree	19.3	7.7	
Disagree	3.5	1.2	
Physician tells bad news in a sensitive and caring manner (49)†			
Strongly agree	61.0	75.9	0.002
Somewhat agree	28.0	18.2	
Disagree	11.0	6.0	
Physician listens to what the patient has to say about illness (62) †			
Strongly agree	73.2	85.4	0.008
Somewhat agree	25.0	12.4	
Disagree	1.9	2.1	
Patient participates in decisions about care (66)†			
Strongly agree	74.1	85.8	0.01
Somewhat agree	25.0	12.2	
Disagree	0.9	1.9	

Figure 5: Terminally Ill African-American and White Patients Report of the Quality of the Patient-Physician Relationship, Advance Care Planning and Preferences. Smith (2007). Adapted from <https://www.ncbi.nlm.nih.gov.ezproxy.umassmed.edu/pmc/articles/PMC2219809/>

All terminally ill patients, initial interview (n = 803)	African American (n = 115)	White (n = 688)	P value
Has an advance care plan (any of 4 below)	47.0	79.5	<0.001
Has living will	14.9	54.9	<0.001
Has health care proxy	22.1	51.3	<0.001
Talked with family about plans for care near the end-of-life	40.2	64.9	<0.001
Talked with physician about plans for care near the end-of-life	21.1	25.9	0.29

Figure 5 (cont): Smith (2007)

Possible Causes for Disparities

- Studies show a disproportionate gap in knowledge about palliative care among minority adults.
- Among African Americans, spiritual/religious beliefs and mistrust of health care system due to past and current injustices are possible causes (Johnson, 2005).
- Among Asians and Hispanics, stigma towards disclosing terminal illness may lead to disparities (Kwak, 2005).



Members of the UMMHC Palliative Care Team
Retrieved from:
<https://www.umassmed.edu/palliative-care/>

Palliative Care Interprofessional Team

- Team approach to patient care
 - Palliative care team works with primary medical team to improve quality of life for patients and families
- Care provided at both inpatient and outpatient settings
 - Examples: clinic, home, long term facility, hospice
 - Care provided along entire disease process from initial diagnosis to last breath

Palliative Care Interprofessional Team

- **Physician & Advanced Practice Provider (NP/PA)** → Helps plan and coordinate care with treatment team; prescribe treatments for symptoms including pain, nausea, depression, anxiety, etc.
 - Challenges
 - Under-utilization and referral
 - Difficult first encounters with patients
- **Palliative Care Nurse** → Helps manages day-to-day symptoms and educates about strategies to manage condition; ensures access to medicine and treatments; may be providing care in the home
 - Challenges
 - Especially in the home - creating intimate relationships with patients
- **Social Worker** → Assesses needs of patient/family and coordinates available resources; may provide counseling to patients and arrange family meetings; reviews insurance coverage and community resources, making suggestions and referrals
 - Challenges
 - May have to help families resolve differing wishes
 - Work within the confines of health insurance coverage and community resources
- **Therapist** → Helps process feelings about diagnosis and symptoms; advises on strategies to relieve grief, depression, anxiety, etc; counsels on relationship and emotional issues with loved ones
 - Challenges
 - Patients and families may be in denial of diagnosis and/or prognosis
- **Physical/Occupational Therapist** → Help maintain/improve physical strength and ability to perform activities of daily living; refer equipment or modifications for safe mobility, teach techniques and exercises, and may assist in body positioning for pain relief
 - Challenges
 - Patients and families may worry about fatigue



Figure 7: Chaplain with patient. Retrieved from <http://archive.knoxnews.com/entertainment/family/families-face-difficult-decision-as-hospice-care-grows-ep-360093919-356686891.html>

Palliative Care Interprofessional Team (cont.)

- **Pharmacist** → Provides medications for symptom relief and educates about safety, symptoms, and interactions
 - Challenges
 - Safe medication reconciliation
 - Meeting patient's EOL care goals while managing distressing symptoms (e.g. pain vs. sedation)
- **Dietician** → Assist patients to optimize dietary intake and develop nutritional plan focused on patient's wishes; educates patient and family on treatment plan, patient's current disease, and quality of life as it applies to nutrition
 - Challenges:
 - Cessation of eating and drinking as normal part of dying process (occurs days-weeks prior to death)
 - Communicating to loved ones the decision to stop eating/artificial feeding during EOL care
- **Chaplain/Spiritual Worker** → Assists with spiritual matters; balances out emotional and/or spiritual vulnerabilities of patients and healthcare providers
 - Challenges:
 - Exposed to intense emotions surrounding spirituality
 - Moderate compassion fatigue on the team
- **Community Health Worker** → Participate & coordinate community outreach events to inform them about palliative care; encourage community members to be proactive in their health
 - Challenges:
 - Must be flexible to offer a variety of services to those they serve (interpreter, cultural)
 - Often must work to gain trust of community members to address unique care needs, say in immigrant communities
- **Child Life Specialist** → Pediatric Palliative Care team; uses play, dialogue, art, music, writing, to help child understand their illness.
- **Alternative Care Specialists** --> Includes Care Specialists such as: Music therapy, Art Therapy, Massage therapy, Chiropractor, etc.
 - Challenges:
 - Despite evidence-based therapeutic benefit, are only gradually being incorporated into modern palliative care and may not be covered by insurance

Advocacy Work in Palliative Care



Figure 8: Woman advocating Congress for PCHETA bill. Retrieved from <https://www.stbaldricks.org/blog/post/tell-congress-to-support-the-new-pediatric-palliative-care-bill>

Major Areas for Advocacy

- **Education** for community members and health care professionals about what Palliative Care is and what it can do
- **Insurance reform** so that more palliative care services are reimbursed and thus more accessible
- **Community interventions** related to palliative care - to raise awareness and positively impact populations in need (ie. elderly, veterans)
- **Quality** of palliative care across the country - how conversations about end of life choices and patient autonomy standardized
- **Access** to palliative care for patients and their families regardless of geography or socioeconomic status

Honoring Choices

- Non-profit organization focused on patient rights to plan and receive care that honors their values & choices
- Advocates for a structured and universal approach to health care planning such as
 - Choosing a health care agent in a health care proxy
 - Importance of palliative care
- Provides patients and providers with guides for approaching difficult conversations about palliative care/serious illness

Palliative Care and Hospice Education and Training Act (PCHETA)

- Introduced in the House and Senate on 03/22/2017, has passed the House
- This bill would:
 - Help address workforce shortages of palliative care clinicians
 - Improve quality of care
 - Improve amount and quality of research into palliative care
- Organizations like AAHPM are currently lobbying to pass this bill

Patient Choice and Quality Care Act of 2017

- Introduced in the House and Senate on 06/12/2017
 - Would require Medicare/Medicaid to create/test new model for advanced planning in serious illnesses

How can providers be involved in advocacy for palliative care?

- **Internal advocacy**

- Working in interdisciplinary teams promoting palliative care consults throughout different floors and departments in the hospital
- Educating all healthcare staff about what palliative care is and when they can help
- Creating pamphlets for patients and families to read and learn more about palliative care

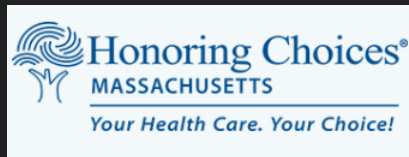
- **External advocacy**

- Contact lawmakers and lobby for legislation like the PCHETA bill to pass
- Community engagement to raise awareness for palliative care and advanced care directives

YOUR Homework

- Yes, we are giving **you** homework!!!
- Prepare a 30 second “elevator speech” about palliative care
- This way, you’ll be able to explain what Palliative Care is to address commonly held misconceptions

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Questions?



Figure 9: We would also like to thank Hazel for her kisses during the PHC

Disparities in Use of Hospice Services

- Studies show lower rates of hospice use for minority older adults.
- Among medicare beneficiaries who died in 2010, 45.8% of Whites used hospice care, compared to 34% of African Americans, 37% of Hispanics, 28.1% of Asian Americans, and 30.6% of Native Americans (Medicare Payment Advisory Council).
- Research on nonhospice-based palliative care is minimal.