Palliative Care in the ED

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Disclosures

- Contracted vascular access research sponsored by Teleflex Inc, 410 Medical, Hospi Corp

Objectives

Following this lecture, the learner will be able to:

- Define and understand the importance of palliative care (PC) and hospice
- Recognize the controversies and conflicts relating to PC in the emergency department
- Understand the concept of "trajectories of dying," and how it applies to PC
- Utilize PC concepts in the care of EM patients

The Traditional Paradigm

- "Saving Lives"
- "Death is the Enemy"
- "I failed – my patient died"

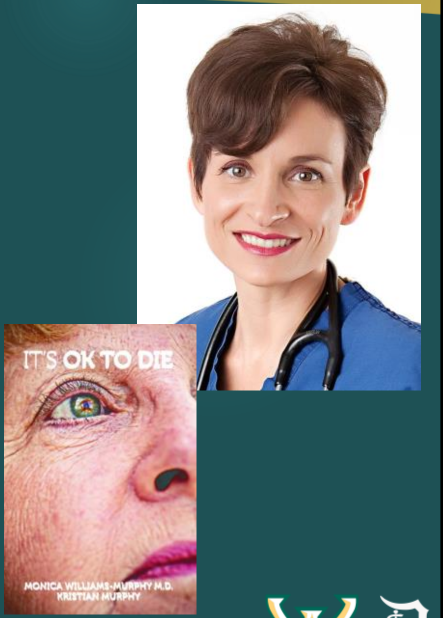
The New Paradigm

- Death is not always the enemy
  - Goal can be to lessen avoidable suffering
- "Two Saves"
  - Extend life / prevent death when disease can be treated
  - Relieve suffering when disease is not curable

Beemath A, Zalenski RJ. "Palliative emergency medicine: Resuscitating comfort care." *Ann Emerg Med.* 2009;54(1):103-105.

"A Road Map Home"

- The story of three patients treated in the ED during end-of-life, and decisions made by their families.
- "Knowing where you are and what to expect on the path of life sometimes changes everything."
- "An ***unexpected*** death is always an emergency."
  - If no one ever told you that you are going to die, then it will be unexpected



https://www.kevinmd.com/blog/2012/12/life-underestimate-power-map.html

2011

Palliative Care – Definition

- "An approach that improves the quality of life of patients and their families facing the problem 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" (World Health Organization).

https://www.who.int/cancer/palliative/definition/en/

Palliative Care

- provides **relief from pain** and other distressing symptoms;
- **affirms life and regards dying as a normal process**;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients **live as actively as possible until death**;
- offers a support system to **help the family cope** during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will **enhance quality of life**, and may also positively influence the course of illness;
- 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 clinical complications.

https://www.who.int/cancer/palliative/definition/en/

Palliative Care

- Provides expert control of pain and symptoms
- Uses the **crisis of the hospitalization** to facilitate communication and decisions about goals of care with patient and family
- Coordinates care and transitions across fragmented medical system
- Provides practical support for family and other caregivers

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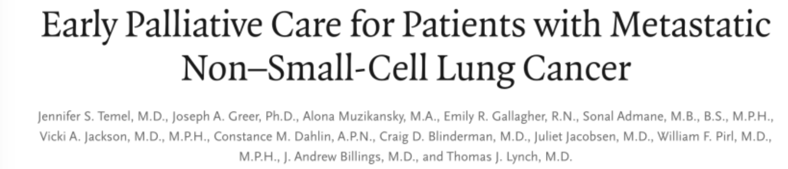


Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer

Jennifer S. Temel, M.D., Joseph A. Greer, Ph.D., Alona Muzikansky, M.A., Emily R. Gallagher, R.N., Sonal Admane, M.B., B.S., M.P.H., Vicki A. Jackson, M.D., M.P.H., Constance M. Dahlin, A.P.N., Craig D. Blinderman, M.D., Juliet Jacobsen, M.D., William F. Pirl, M.D., M.P.H., J. Andrew Billings, M.D., and Thomas J. Lynch, M.D.

- Randomly assigned 151 patients with metastatic lung cancer to receive either standard oncologic care or early palliative care, focused on symptom control and psychosocial support for patients and families, together with standard oncologic care.
- Patients receiving early palliative care had **lower rates of depression** (16% vs 38%), reported better quality of life (p=.03), and better mood scores.
- They also received less aggressive care at the end of life, but surprisingly, had significantly **longer survival** (89 vs. 11.6 months, p<.02) than patients receiving standard care alone.

2010 The NEW ENGLAND JOURNAL of MEDICINE

School of Medicine

Palliative Care…

IS

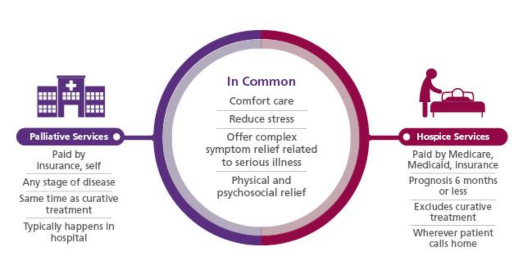
- ✓ Evidence-based medical treatment
- ✓ Vigorous care of pain and symptoms throughout illness
- ✓ Care that patients want *at the same time* as efforts to cure or prolong life

IS NOT

- × "Giving up" on the patient
- × Meant to replace curative or life-prolonging care
- × The same as hospice

Palliative Care vs. Hospice

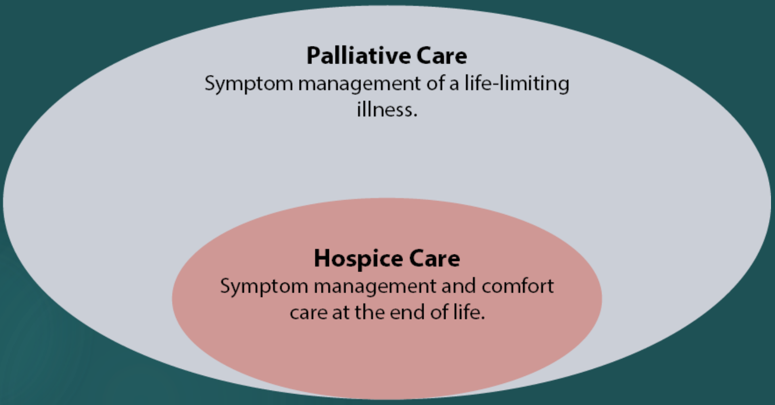
- **Hospice eligibility** requires that **<u>two physicians</u>** certify that the patient has **<u>less than six months to live</u>** if the disease follows its usual course.
- **Palliative care** is begun at the discretion of the physician and patient at any time, at any stage of illness, terminal or not.



Palliative Services
- Paid by insurance, self
- Any stage of disease
- Same time as curative treatment
- Typically happens in hospital

In Common
- Comfort care
- Reduce stress
- Offer complex symptom relief related to serious illness
- Physical and psychosocial relief

Hospice Services
- Paid by Medicare, Medicaid, insurance
- Prognosis 6 months or less
- Excludes curative treatment
- Wherever patient calls home



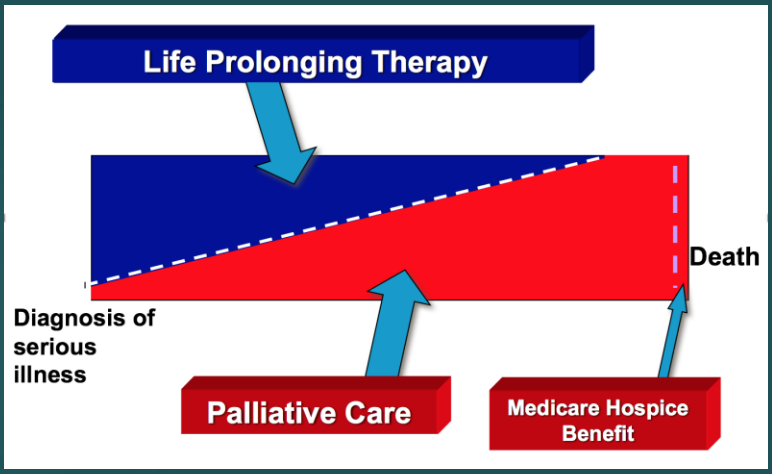
Palliative Care
Symptom management of a life-limiting illness.

Hospice Care
Symptom management and comfort care at the end of life.

Three "C"s of Hospice:

- Comfort
- Communication
- Coordination of care

Palliative Care vs. Hospice



Hospice

- **Palliative care** costs (from office visits to prescription charges) can vary, and are not guaranteed to be paid by Medicare or insurance.
- **Hospice care** costs are paid 100 percent by **Medicare**, Medicaid and private insurance.
  - 90% are Medicare
  - Hospice is the only Medicare benefit that includes pharmaceuticals, medical equipment, 24/7 access to care, nursing, social services, chaplain visits, grief support following a death and other services deemed appropriate by the hospice agency.

Who Dies in the ED?

Leconte (2010)

- 4-month prospective survey in 174 EDs in France and Belgium
- Total of 2,512 deaths
  - Mean age: 73.5 years
  - 50% male
  - 1,970 (81.4%) had chronic underlying disease
- Acute presentations
  - Respiratory, cardiac, neurologic

Leconte P, Riochet D, Batard E, et al. "Death in emergency departments: A multicenter cross-sectional survey with analysis of withholding and withdrawing life support." *Intensive Care Med.* 2010;36(5):765-772.

Who Dies in the ED?

Leconte (2010)

- Life Support initiated = 1781 (73.6%) pts
- Palliative Care initiated = 1373 (56.7%) pts
- A decision to **withhold or withdraw life-sustaining treatments** was made for 1,907 patients (78.8%)
    - The decision was made by a single ED physician in 379 cases (19.9%), and by at least two ED physicians in 1,528 cases (80.1%).
    - Mostly > 80 years old with pre-morbid functional limitations or metastatic cancer
    - Decisions were discussed with family or relatives in 58.4% of cases

Leconte P, Riochet D, Batard E, et al. "Death in emergency departments: A multicenter cross-sectional survey with analysis of withholding and withdrawing life support." *Intensive Care Med.* 2010;36(5):765-772.

Who Dies in the ED?

Kanzaria (2016)

- Retrospective review of National Hospital Ambulatory Medical Care Survey (NHAMCS)
    - 1.3 billion ED visits (1997-2011) with 367,618 deaths in the ED
    - Included both patients who arrived DOA and those who died in the ED
        - 62.7 % were unconscious, in cardiac arrest, or already dead at time of arrival
    - Mortality rates decreased from 0.148 % (1997) to 0.077 % (2011)

Kanzaria HK, Probst MA, Hsia RY. "Emergency department death rates dropped by nearly fifty percent, 1997-2011." *Health Aff (Millwood).* 2016;35(7):1303-1308.

Fewer People Dying in the ED?

- Must be dying somewhere else:
  - Hospice settings
  - Home
  - Inpatient wards
- Do we withdraw ED care less commonly in the US than in other countries?
  - Concern about legal implications
  - Concern about ethical implications
  - Uncomfortable making the decision
  - Still view death as the enemy

Common Concerns from EM Docs

- Equate Palliative Care with Hospice
- Disagree about feasibility of PC in the ED
- "Patients come to ED for symptom control"
- Lack of communication between outpatient and EM physicians
- Conflicted about withholding life-prolonging treatment
- Inadequate training in pain management

Smith AK, Fisher J, Schonberg MA, et al. "Am I doing the right thing? Provider perspectives on improving palliative care in the emergency department." *Ann Emerg Med.* 2009;54(1):86-93.

Obstacles to Palliative Care

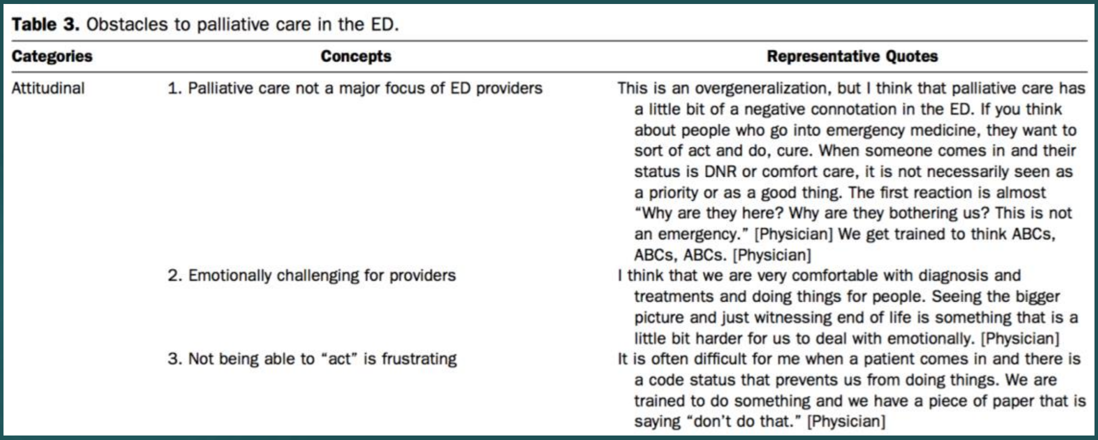
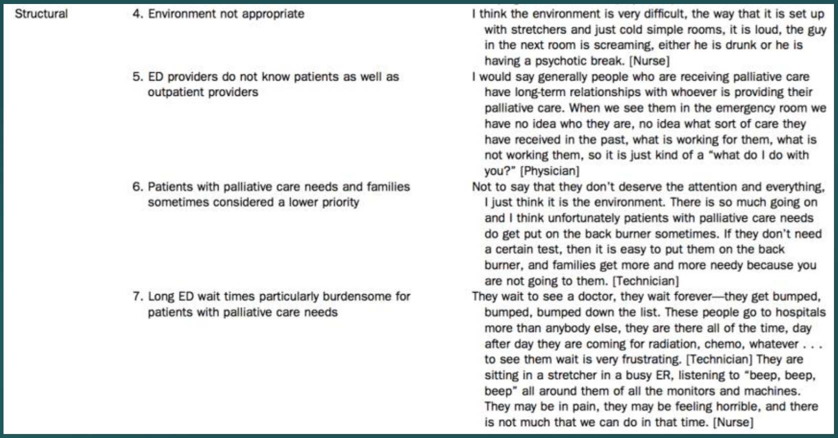


Table 3. Obstacles to palliative care in the ED.

Categories	**Concepts**	**Representative Quotes**
Attitudinal	1. Palliative care not a major focus of ED providers	This is an overgeneralization, but I think that palliative care has a little bit of a negative connotation in the ED. If you think about people who go into emergency medicine, they want to sort of act and do, cure. When someone comes in and their status is DNR or comfort care, it is not necessarily seen as a priority or as a good thing. The first reaction is almost "Why are they here? Why are they bothering us? This is not an emergency." [Physician] We get trained to think ABCs, ABCs, ABCs. [Physician]
	2. Emotionally challenging for providers	I think that we are very comfortable with diagnosis and treatments and doing things for people. Seeing the bigger picture and just witnessing end of life is something that is a little bit harder for us to deal with emotionally. [Physician]
	3. Not being able to "act" is frustrating	It is often difficult for me when a patient comes in and there is a code status that prevents us from doing things. We are trained to do something and we have a piece of paper that is saying "don't do that." [Physician]

Smith AK, Fisher J, Schonberg MA, et al. "Am I doing the right thing? Provider perspectives on improving palliative care in the emergency department." *Ann Emerg Med.* 2009;54(1):86-93.

Obstacles to Palliative Care



Structural	4. Environment not appropriate	I think the environment is very difficult, the way that it is set up with stretchers and just cold simple rooms, it is loud, the guy in the next room is screaming, either he is drunk or he is having a psychotic break. [Nurse]
	5. ED providers do not know patients as well as outpatient providers	I would say generally people who are receiving palliative care have long-term relationships with whoever is providing their palliative care. When we see them in the emergency room we have no idea who they are, no idea what sort of care they have received in the past, what is working for them, what is not working them, so it is just kind of a "what do I do with you?" [Physician]
	6. Patients with palliative care needs and families sometimes considered a lower priority	Not to say that they don't deserve the attention and everything, I just think it is the environment. There is so much going on and I think unfortunately patients with palliative care needs do get put on the back burner sometimes. If they don't need a certain test, then it is easy to put them on the back burner, and families get more and more needy because you are not going to them. [Technician]
	7. Long ED wait times particularly burdensome for patients with palliative care needs	They wait to see a doctor, they wait forever—they get bumped, bumped, bumped down the list. These people go to hospitals more than anybody else, they are there all of the time, day after day they are coming for radiation, chemo, whatever . . . to see them wait is very frustrating. [Technician] They are sitting in a stretcher in a busy ER, listening to "beep, beep, beep" all around them of all the monitors and machines. They may be in pain, they may be feeling horrible, and there is not much that we can do in that time. [Nurse]

Smith AK, Fisher J, Schonberg MA, et al. "Am I doing the right thing? Provider perspectives on improving palliative care in the emergency department." *Ann Emerg Med.* 2009;54(1):86-93.

What is a "Palliative Approach" to EM?

- **Relieve Suffering**
  - Treat symptoms even when pathophysiology is not fixable
- Be open to assessing **patients' preferences**
- Help patients and families to establish **realistic** goals
  - Provide honest information about prognosis
  - Discuss the benefits and burdens of treatment
  - Code status and other advanced directives
- Seek out and recognize opportunities to educate patients and families on methods to **manage symptoms** at home

GENERAL MEDICINE/ORIGINAL RESEARCH

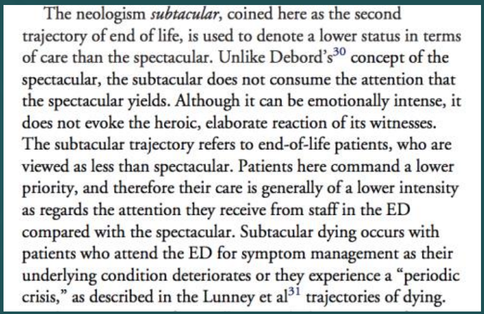
Trajectories of End-of-Life Care in the Emergency Department

Cara Bailey, PhD, RGN, Roger Murphy, PhD, BSc, Davina Porock, PhD, RGN

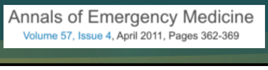
From the School of Nursing, Queens Medical Centre (Bailey, Porock), and the School of Education, Jubilee Campus (Murphy), The University of Nottingham, Nottingham, UK.

Dr. Bailey is currently affiliated with Nursing and Physiotherapy, Health and Population Sciences, University of Birmingham, Birmingham, UK.

- "Two distinct trajectories of end-of-life care were identified in the ED; the **spectacular** and the **subtacular**."



The neologism *subtacular*, coined here as the second trajectory of end of life, is used to denote a lower status in terms of care than the spectacular. Unlike Debord's[30] concept of the spectacular, the subtacular does not consume the attention that the spectacular yields. Although it can be emotionally intense, it does not evoke the heroic, elaborate reaction of its witnesses. The subtacular trajectory refers to end-of-life patients, who are viewed as less than spectacular. Patients here command a lower priority, and therefore their care is generally of a lower intensity as regards the attention they receive from staff in the ED compared with the spectacular. Subtacular dying occurs with patients who attend the ED for symptom management as their underlying condition deteriorates or they experience a "periodic crisis," as described in the Lunney et al[31] trajectories of dying.



Annals of Emergency Medicine
Volume 57, Issue 4, April 2011, Pages 362-369

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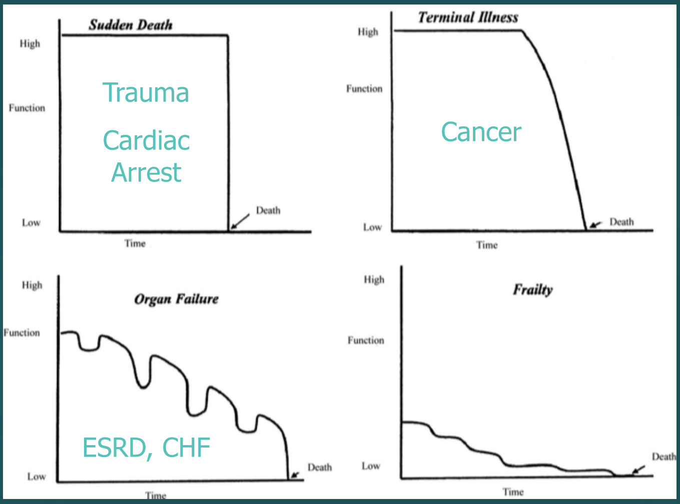
- “Patients and family members experiencing end-of-life care in the ED have **distinctly different care** because of the nature of these two trajectories, frequently resulting in dissatisfaction for staff and distress and frustration for patients and their relatives.”
- “The ED is priority-driven, focused on resuscitation and the prolongation of life. As a result of the **consuming nature of the spectacular death**, a reluctance to build relationships with the dying, and a lack of educational support, the care needs of patients in the **subtacular trajectory are somewhat neglected**.”

Annals of Emergency Medicine
Volume 57, Issue 4, April 2011, Pages 362-369

Dying Trajectories

- Most patients who die in the hospital are on an **accelerated** dying trajectory
- Understanding these trajectories may help patients and families understand likely outcomes and prognosis
- Frame the decision of what should be done **this time** and what we should expect **next time**

Trajectories of Dying



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Treatment Effectiveness x Patient Preferences

Patient / family want "aggressive" Tx (aTx)

ER suggests aTx		+	-
	+	A	B
	-	C	D

Examples

A : "Classic" emergent condition (e.g. ruptured appendix)

B : Jehovah's Witness with GI bleeding

C : Dying of brain mets - family wants intubation

D : Same as C, but family asks for comfort care

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The Last 3 Months of Life

- 12% of adults aged ≥65 who died during a six-month period **attended the ED ≥3 times in the last 3 months of life**, representing 43% of all such ED attendances.
- 251 decedents had primary diagnosis of cancer (36.5%), 180 circulatory disease (26.2%) and 112 respiratory disease (16.3%).
- Older adults with respiratory disease and/or multiple comorbidities were more likely to attend the ED frequently at end of life.
- Association between community nursing visits and frequent ED attendance may reflect **short task-based visits from multiple nurses**.
- A model of care involving a key health professional to coordinate care may reduce frequent end of life ED attendances.

Bone AE, Evans CJ, Henson LA, et al. "Patterns of emergency department attendance among older people in the last three months of life and factors associated with frequent attendance: a mortality follow-back survey." *Age and Ageing*. 2019;0:1-8. doi:10.1093/ageing/afz043.

Rhea Heil Seasons Hospice Unit

- First Dedicated Inpatient Unit in MI
- 10-bed unit on 2nd floor of Sinai-Grace Hospital (Detroit, MI)
- 24-7 Admission of Hospice Patients
- Open Access Hospice Model

https://www.dmc.org/services/hospice

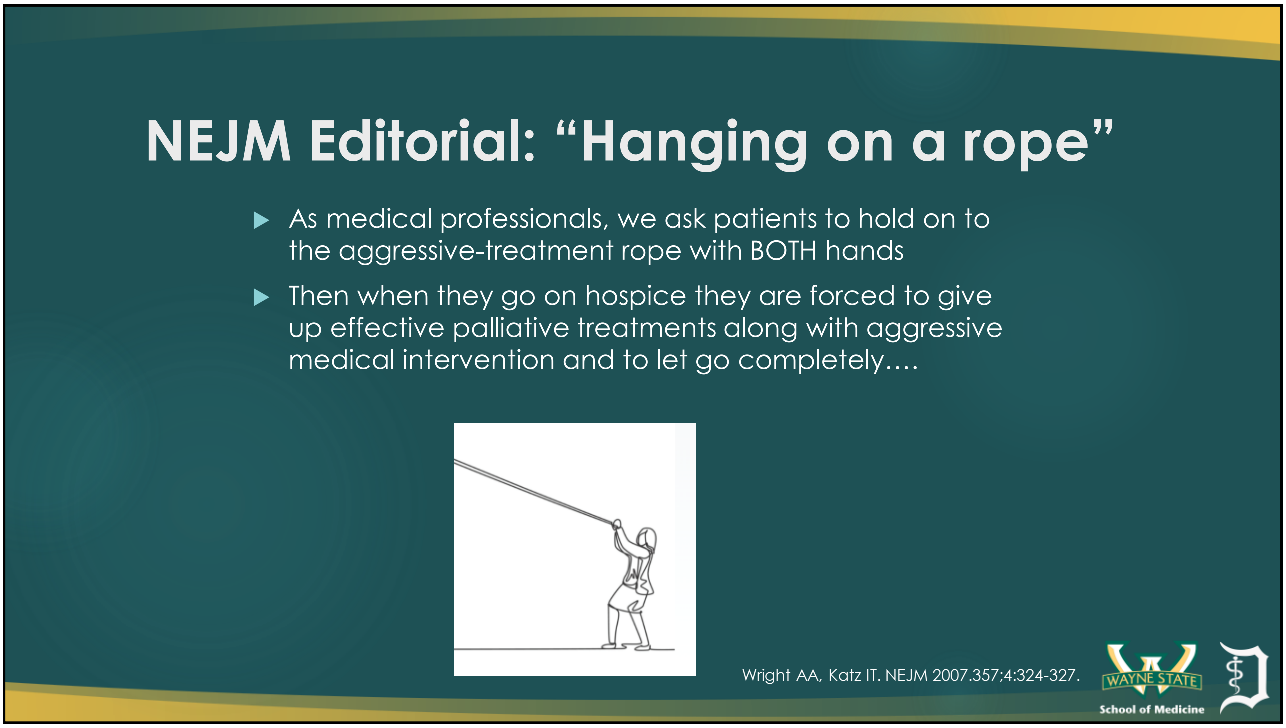
Indications for Short-Term Hospice Stay

- uncontrolled pain
- decreased blood pressure
- decreased urine output
- intractable nausea
- vomiting and/or diarrhea
- respiratory distress
- decubiti or other skin lesions/wounds
- other symptoms that are unmanageable at home (active seizures, active bleeding, etc.)
- need for respite care (up to five days)
- the family doesn't want the patient to die at home

https://www.dmc.org/services/hospice

Open Access Hospice Model

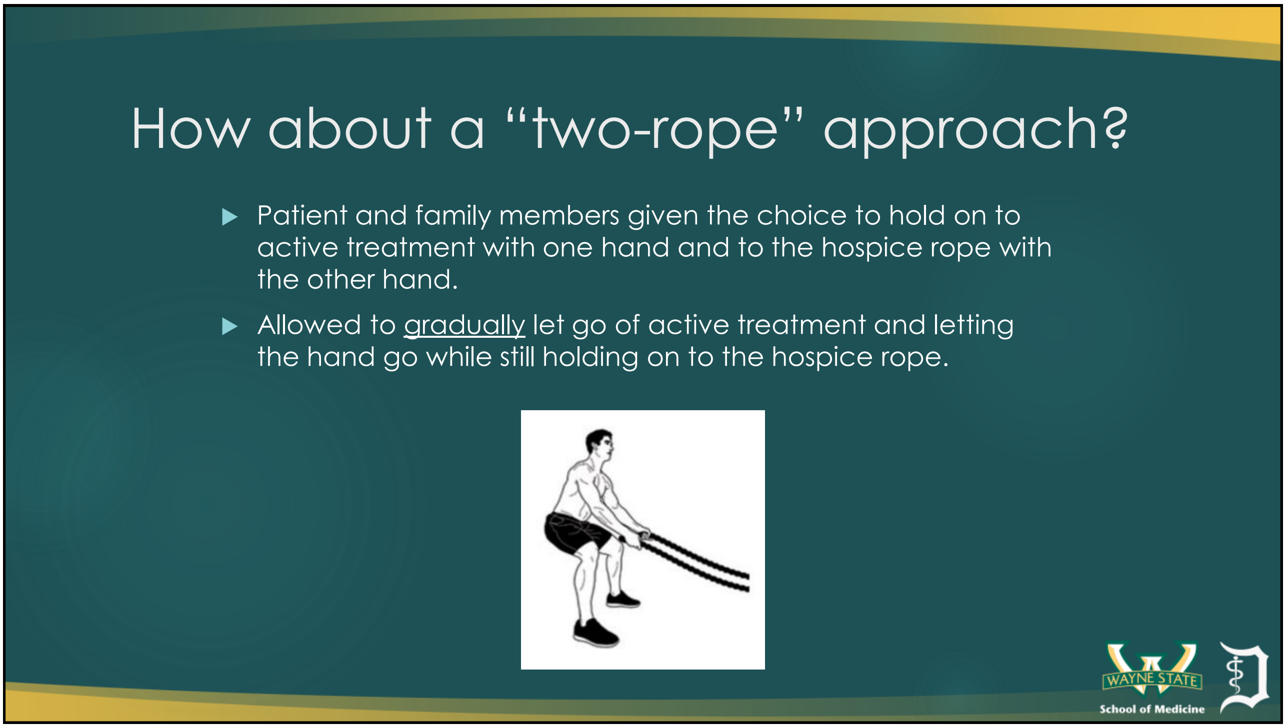
- Historically, hospices created barriers by **requiring** patients to have a DNR order, and to forego:
    - IV antibiotics
    - TPN
    - Cardiac drips
    - Mechanical ventilation & aggressive respiratory care
    - Palliative radiation and other forms of care
- Open Access **allows** patients currently receiving treatments such as IV antibiotics, TPN, IV hydration, respiratory care, cardiac drips, palliative radiation, and other forms of treatment to **simultaneously** access hospice care.
- Provides patients with **TIME** to process and understand their prognosis, and to explore options and resources for end-of-life management



NEJM Editorial: “Hanging on a rope”

- As medical professionals, we ask patients to hold on to the aggressive-treatment rope with BOTH hands
- Then when they go on hospice they are forced to give up effective palliative treatments along with aggressive medical intervention and to let go completely….

Wright AA, Katz IT. NEJM 2007.357;4:324-327.



How about a “two-rope” approach?

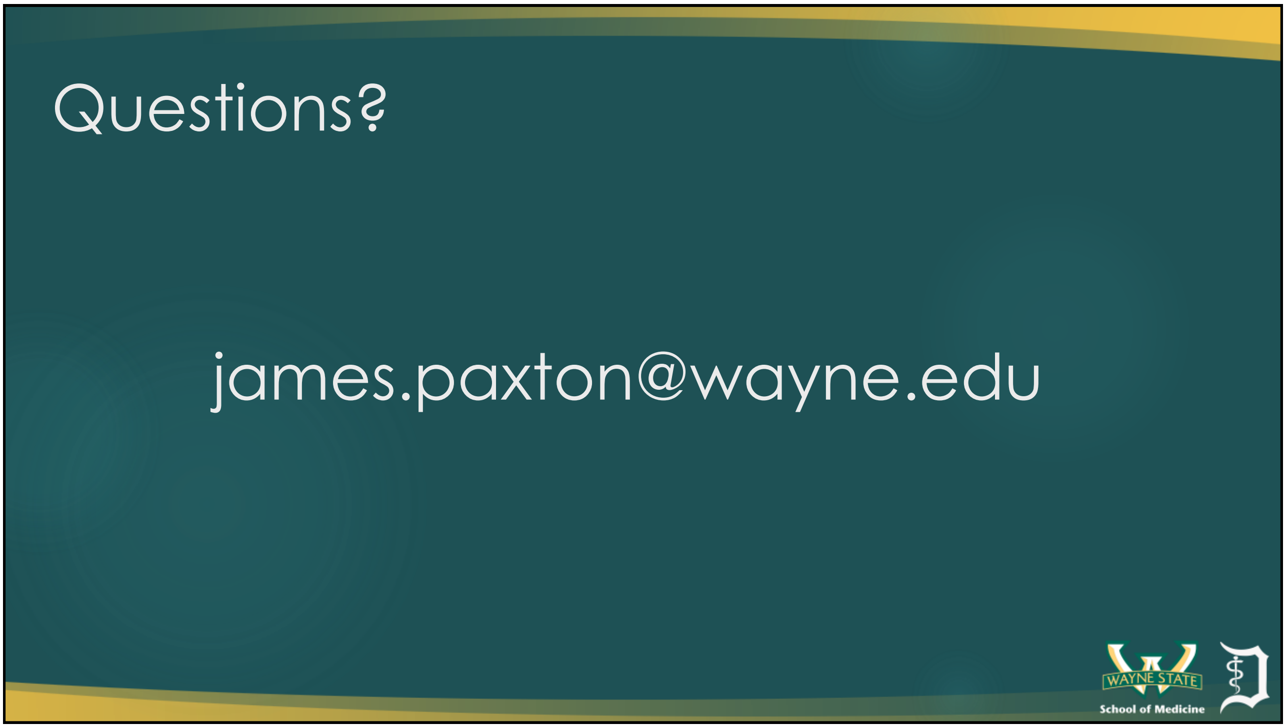
- Patient and family members given the choice to hold on to active treatment with one hand and to the hospice rope with the other hand.
- Allowed to gradually let go of active treatment and letting the hand go while still holding on to the hospice rope.

Important Concepts

- Establish the Prognosis
- Obtain Informed Consent
- Respect Patient Autonomy
- Assess Patient Decision-Making Capacity
- Establish Advanced Directives
- Support Dignity

Conclusions

- Defining goals of care is more than just DNR / DNI
- Take time to explore the patient's goals / expectations for:
  - Extending time
  - Relief of suffering
  - Providing comfort
  - Privacy (remain at home) vs. Nursing Home
- Help patients and families make critical decisions
- Explore options but execute wishes



Questions?

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