conversation and choice: navigating serious illness

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objectives

- To better empower patients to make decisions consistent with their values

- To expand understanding of palliative care and hospice and to promote these choices to patients when appropriate

- To explore barriers to end of life conversations and decision making

- To begin the conversation…
what type of care do seriously ill patients want at the end of life?

- 80% of patients say they wish to avoid hospitalization and ICU care in the last months of life, but many patients are getting more intensive care:
  - Increased percentage of ICU hospital days in the last 6 months of life
  - Increase in number of patients who saw 10 or more physicians in last month of life
    - Dartmouth Health Atlas, data from 2007
What type of care do seriously ill patients want at the end of life?

- 75% of Americans say they want to die at home
- < 50% of Americans die at home
  - (CDC data, 2005)
Percent distribution of decedents age 65 and over by place of death, 1989–2009

NOTE: “Other” includes hospital outpatient or emergency department, including dead on arrival, inpatient hospice facilities, and all other places and unknown. Beginning in 2003, the term “long-term care facility” was added to the nursing home check box on the death certificate. Reference population: These data refer to the resident population.

the care patients receive at the end of life: concordance with wishes

- In a study of 458 hospitalized patients over a 2 year period:
  - 75% preferred to die at home
  - Of the 123 patients who died, 80% died in an institutional setting
    - Hospital, nursing home
  - Concordance with wishes only 37%

  - Fischer, et al. Where do you want to spend your last days of life? Low concordance between preferred and actual site of death among hospitalized adults. Journal of Hospital medicine. 2013 Apr; (4): 178-83
If you die at home receiving hospice care, you are more likely to have:

- adequate emotional support
- adequate pain control
- adequate bereavement support for your family and caregivers

Teno, et al. Family Perspectives on End of Life Care at the Last Place of Care. JAMA. Jan 2004:291 (1); 88-93
Pause:

- Dying at home on hospice is used as a proxy for quality end of life care but

- There is no “right” way to die
  - Dying at home may not be practical, or may not be what is most comfortable to an individual patient

- The goal is to individualize patient care and present choices that are consistent with patient values and realistic for their needs
changes in medicine: 1940s

- advancement of curative and life prolonging treatments
  - antibiotics (PCN discovered 1928)
  - chemotherapy (1940s)
  - mechanical ventilation (1940s)
Hospice and palliative care evolved in response to curative practices of medicine that did not fully address the scope of patient suffering, especially for patients who were dying.

Dame Cicely Saunders propelled the modern hospice movement with her successful efforts in the 1950s and 1960s to develop specialized care for dying patients.
to palliate

- from medieval Latin: *palliare* - to cloak
Principles of hospice and palliative care

- Provide patients and families with the information they need in an ongoing and understandable manner, so that they can grasp their condition and treatment options.

  - includes eliciting values and goals
  - reassessing benefits/burdens of treatment
  - ensuring that decision-making process accounts for changes in pt’s condition
Principles of hospice and palliative care

- Prevention and relief of suffering
  - Physical, emotional, spiritual, practical, social
  - Concept of total pain: the experience of multidimensional suffering

- Promote advance care planning
  - Maximizing choice in how patients progress through illness and dying

- Affirm life and regard dying as a normal process
"I once asked a man who knew he was dying what he needed above all in those who were caring for him. He said, 'For someone to look as if they are trying to understand me',"

Dame Cicely Saunders
Hospice care is based on an acceptance that the underlying disease process will progress and is not curable. Curative or disease modifying treatments are no longer beneficial (either not offered or not chosen by the patient).

Palliative care may be provided concurrently with curative or disease modifying treatments.
Additional principles of hospice and palliative care

- Recognition of the family/caregiving context
- Empowerment
  - Decision making: patients can make the best decisions for themselves with the right information and support
  - Providing care at the end of life: empowering families with caregiving skills, in combination with their knowledge of the patient, that allow for compassionate care at home
Delivery of hospice care

- Provided primarily by home health agencies and hospice agencies
  - Interdisciplinary team: RN, SW, LNA, volunteer, chaplain, MD
- May be delivered in any setting (home is majority, but also nursing home, hospital, or hospice facility)
- Most hospice care provided through Medicare Hospice Benefit
  - Must have prognosis of < 6 months to qualify
  - Patients may live longer than six months and remain on hospice, but the hospice team must continue to document a limited prognosis
Common misperceptions about hospice

“Hospice just gives you a lot of morphine until you die”
- Hospice practice has a vigilant focus on symptom management which often requires use of opioid medications
- Use of medications is always in response to or in anticipation of a symptom or a clinical change in the disease process.

Hospice provides 24 hour nursing care in the home
- Hospice is visit-based for routine care
- Hospice can provide 24 hour nursing coverage on a short term basis only.
Delivery of palliative care

- Academic medical specialty, now a board certification
- Provided primarily in hospitals as a consult service
  - Consults typically for complex symptom management, determining goals of care, helping patients and families adjust to serious illness, and when there is a strong sense that non-beneficial treatment is being provided
- Also provided as adjunctive care in outpatient clinics
  - Oncology, cardiology, neurology
- May be offered through home health agencies as a “bridge” to hospice
Quality of hospice and palliative care: meaning for patients and families

- **Palliative care:**
  - patients may live longer than those receiving standard treatment
  - higher quality of life scores
  - less depression

- **Hospice care:**
  - lower mortality for spouses of patients cared for by hospice
  - Better pain and symptom management at the end of life
  - Better quality of life in the last weeks of life
Value of having end of life conversations

Costs may be 35% lower among patients reporting end of life conversations, with an average savings of $1000 per patient in the last week of life


The case of Lacrosse Wisconsin’s Respecting Choices program

- 96% advance directive completion rate
- Lowest rate of acute care utilization in the last year of life
  - (Dartmouth Atlas, 2012)
Having the conversation about serious illness

Physician barriers/factors

- End of life communication training and comfort level in discussing end of life issues

- Timing of discussion
  - Usually too late (on average within a month before death)
  - This delay limits access to the proven benefits of hospice
    - 15% of hospice patients referred in their last week of life

- Prognostic uncertainty

- Addressing psychosocial concerns
  - Responding to emotion
Having the conversation about serious illness

- Patient barriers/factors
  - Expectations
    - Patients expect their doctors to initiate discussions
  - Emotions
    - Anxiety and denial may limit conversation (though can be normal coping skills)
    - Contributes to misunderstanding as much as inadequate disclosure
“Cheer up Mom... They say dead is the new 80.”
How to start the early conversation about illness, death, and dying

among family, friends, professionals...
Triggers for conversation about serious illness

- prognosis related
- acute illness or hospitalization
- serious illness or death in a friend or family member
- progression of serious disease despite treatment
- any expression of discomfort or distress in a patient with serious or chronic illness
- questions about Act 39: Patient Choice and Control at the End of Life
Mr. R

- Home visit consult for a 77 year old man with advanced COPD

- 8 years dependent on oxygen

- Recent hospitalization for COPD exacerbation, home for 2 weeks, “doing very poorly”
  - Short of breath
  - Can’t get upstairs
  - Can’t leave the house to see his doctor
Mr. R: a triggered conversation about goals

- He reports being fearful and frustrated with his symptoms

- His family sits at the kitchen table with me, weighing in on the dramatic change they have seen and how worried they are about him

- **What worries you the most?**
  - Feeling this way, so short of breath and so weak I can’t take care of myself
What is your understanding of your illness?

I know it is serious. Jesus, I’ve been on oxygen for 8 years! It’s never been this bad before. I know it is a disease that will get worse over time, even kill me at some point.

I agree with that information, and I am worried about how short of breath you are. We will work on a plan to help you get better and feel better. If we can’t turn around what is happening in your body, it may be that you entering into a later phase of your illness, even a terminal phase.

SILENCE

Have you thought about decisions you might face if you become sicker?
My doctor has given me those advance directive papers a hundred times and you know what? I always threw them into the trash!

Well, I am ready now. Let’s do it.

We took out the advance directive form and reviewed CPR and intubation, both of which he chose not to receive in the event of a sudden or rapidly progressive cardiopulmonary emergency.

Advance directive and DNR order completed.
Starting the conversation about serious illness

- Allow silence

- Give direct and honest prognostic information

- Acknowledge and explore emotions

- Focus on quality of life, goals, fears and concerns
  - Patients have other goals besides living longer
Conversations about serious illness: basic approaches

- “Ask-tell-ask” approach
  - Ask patient their understanding
  - Tell what needs to be explained in straightforward language
  - Ask what the patient has heard from the conversation

- Tell me more
  - Whenever you are stuck or not understanding what a patient is telling you
Conversations about serious illness
from a draft of the Serious Illness conversation Guide, Ariadne Labs, 2014

- **Understanding:**
  - What is your understanding of your illness?

- **Information**
  - How much information would you like about what is likely to be ahead with your illness?
    - Do you want to talk about the future?

- **PROGNOSIS**
  - Share prognostic information, tailored to preferences
- **Goals**
  - If you get sicker, what are your most important goals?

- **Fears/Worries**
  - What worries you most about the future? (about your health, or not)

- **Function**
  - What abilities are so critical to your life that you can’t live without?

- **Trade-offs**
  - What are you willing to go through for the possibility of living longer?

- **Family**
  - What does your family know about your priorities and wishes?
Benefit vs burdens: Ms J

- 65 year old woman with Ovarian cancer and gastric outlet obstruction

- Is your current level of symptom management acceptable?
  - It's OK- the combination of medications have really helped but I still feel sick.

  Daughter on speakerphone: Mom, we talked about the venting G tube. I looked it up online and it seems to be a simple procedure.

- Have you discussed this procedure with any of your doctors?
  - I have. My understanding is that it doesn’t always work.
    - Daughter: It could help you feel better. And they say it's simple.
  - Honey, I don’t want a “simple procedure”. I don’t want to get into an ambulance and drive 1 hour to the hospital…. I just don’t want to do that”.

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Ms. J

- What is most important to you right now, in the time you have left?
  - To be at home, with my husband and the dog. To eat and drink the little bit that I can.

- What is your understanding of the future?
  - “I know what when I stop my IV fluids, my time will be short…its going to be a hard decision. I don’t know how I will make that decision… maybe when I am just so weak and uncomfortable…”
  - Her husband and DPOA ultimately made the decision to stop her IV fluids, a potentiality they were both aware of.
In summary

- We can educate and empower patients to facilitate medical decision making and receive goal consistent care.

- Hospice and palliative care resources can support this process and provide high quality, holistic care for patients with serious illness.

- The conversation can be started in a variety of ways, at a variety of times, with a variety of people...
Questions?

Thank you