Shaping Demand: Respecting Individual’s Wishes for End of Life Care

Hospital Flow Professional Development Program

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Disclosure

- Faculty at IHI for the Conversation Ready initiative
Objectives

After this session, participants will be able to:

- Identify the five Conversation Ready principles and examples of each
- Describe how this approach for advanced illness planning supports your hospital system’s strategies for patient-centered, value-based care
- Describe strategies to engage patients and family members in discussions to understand what matters most to them at the end-of-life
Show of hands
Why is there a gap?

It’s always too early... until it’s too late
The gap matters to clinicians too

**Shared Decision Making**

- Clinicians decide
  - No patient input
- Patient decides
  - No clinician input
Conversation Ready Principles

- Engage
- Steward
- Respect

Exemplify

Connect
Conversation Ready Principles

1. **Engage** with our patients and families to understand what matters most to them at the end of life
2. **Steward** this information as reliably as we do allergy information
3. **Respect** people’s wishes for care at the end of life by partnering to develop a patient-centered plan of care
4. **Exemplify** this work in our own lives so that we fully understand the benefits and challenges
5. **Connect** with patients and families in a culturally and individually respectful manner
Overview

Building reliability
- System
  - Population health management
- Individual
  - Improving conversations

Engage  Steward  Respect
Exemplify  Connect
Advance care planning for a patient

Patient comes to a health system

Clinician A
- Usually outpatient
- **Engage**, form a relationship with the patient
- **Steward** advance care planning data:
  - Health care proxy
  - Conversations

Serious illness
- Organ failure
- Terminal illness
- Frailty
Figure 1. Trajectories of dying.

12

8% had a trajectory of dying of “Other” and are not shown here
Advance care planning for a patient

Patient comes to a health system

Serious illness
Organ failure
Terminal illness
Frailty

Nears the end of life

Active dying

Death

Clinician A
• Usually outpatient
• Engage, form a relationship with the patient
• Steward advance care planning data:
  • Health care proxy
  • Conversations
  • MOLST

Clinician B
• Often inpatient, often no preceding relationship with the patient
• Engage, benefit from Steward, ensure care is congruent with wishes → Respect
The value of advance care planning

- End-of-life conversations are associated with...
  - Better quality of life
  - Care that is more consistent with patient preferences
  - Improved bereavement outcomes for family

- “Strong preponderance of evidence shows no increased depression, anxiety, hopelessness”

- American College of Physicians High Value Care Advice
  - Have conversations with patients with serious illness

Towards population health management

- Consensus about “serious illness”
  - Mortality models – eprognosis.ucsf.edu
  - Specific disease criteria
  - Clinician gestalt – “surprise question”

- Specific actions
  - Health care proxy
  - Conversations about:
    - Illness, prognosis
    - Options, incl. palliative care and hospice
    - “What matters most”
  - Appropriate use of MOLST

- Tracking, measuring, reflecting
Making it real

- “Seriously ill” = ≥65yo AND Gagne 47% AND Levine 42%*
- BIDMC’s primary care practice

~42,000 patients
~8,200 are ≥65yo
~400 "seriously ill"

* See eprognosis.ucsf.edu for the Gagne and Levine calculators
Challenges

- Are we identifying the right patients?
- Learning about the consequences when it’s not done well
  - Lack of a feedback loop
- Are we able to do this for everyone who needs it?
  - Time
  - Hot potato
We have to develop patient-centered approaches

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Am I taking away hope? Does this patient trust me?

Let's talk about your illness

Medical information

Relationship and Emotions

Do I trust this person? Does she recognize how this will affect my life?

What are my options?
Choosing a health care proxy
• Encouraging patient-proxy conversation

Discussing serious news

Understanding what matters most
• Goals, hopes, fears, worries, tradeoffs

Shared decision-making about treatments

Helping the patient talk with their proxy/family

Introducing palliative care

Introducing hospice

Introducing and completing a MOLST form
Mr. Smith

- 76 year old man, PMHx severe COPD on home O\textsubscript{2}, CHF, a-fib, and CKD, is admitted to the hospital with pneumonia. Delirious and in respiratory distress. Hospital contacts his next of kin – daughter – to let her know he might need intubation and ICU admission.

- She has never talked with him about what he’d want if he got really sick. She thinks he wouldn’t want to be on life support, but she’s really not sure. She is really worried about him, but she’s also stressed about trying to figure out what the right thing is to do.
Surrogate medical decision makers

- Of patients 65 and older, by 48hrs of hospitalization…
  - 47% need surrogate involvement for decision making
  - 23% have all decisions made by a surrogate

- Types: Health care proxy, next-of-kin, legal guardian

- Conversation should follow choosing a health care proxy
  - Deathoverdinner.org
  - StoryCorps App
  - Conversation Project Starter kit

Torke et al., JAMA Intern Med 2014
Primary care proxy improvement work

Summer 2014
39% proxy chosen

2700 proxies later…

Fall 2016
~85% proxy chosen
Exemplify

- 1 hour interactive workshops
  - Fill out the Proxy form and plan a conversation
  - Feedback and take-aways:
    - “do this across the hospital,” “interactive, practical”
    - “it was helpful to learn more about Proxies, I need to select one”
    - “it’s never too soon to have the conversation, I need to have it”
    - “I need to address proxies more with my patients, and have more conversations”

- “I have done this myself, there were some bumps, but overall, it is a tremendous gift I have given to myself and to my family.”
Mr. Smith

- Intubated, admitted to ICU, given broad spectrum antibiotics, slowly improves over a week. Extubated and transferred to the floor, but is very debilitated. Delirium clears and he is able to complete a health care proxy form just prior to discharge to a rehab.
- The hospital teams wonder about his code status given his advanced lung disease, but they defer further discussion to the outpatient setting.
- Several months later he follows-up in clinic. His daughter accompanies him.
Reframing

- The clinician wants to talk with him about “code status”
- To have confidence a decision about end of life care is informed, we need to ensure they have been through the *process* of advance care planning.
  - Becoming informed is a process
- Consider asking 3 questions…
  1. “How much do you like to know about your medical problems? All the details, just the basics, or something in between?”
  2. “How do you like to make medical decisions? By yourself, with others?”
  3. “Have you thought about the kind of care you’d want if you got really sick some day?”
Discussing serious news

- Patients often don’t understand their situation
  - ~70+% with solid metastatic cancer unaware of chemo’s palliative intent

- This is in part because doctors often withhold information
  - Patients with cancer who wanted a survival estimate
    - 37% got a frank estimate
    - 63% got no estimate, or a conscious over- or underestimate

- It’s hard for us to be accurate
  - Longer patient-physician relationships can → greater error and optimism

Mr. Smith

- He says he wants the details and wants to include his daughter in conversations. He hasn’t thought a lot about it, but he knows he doesn’t want to become “a vegetable on machines.”

- He asks you: “How long have I got doc? I’m not sure how many more pneumonias I can take.”

- You don’t have time for a long conversation today, and you need more information about his prognosis. You plan another visit in 2 weeks and encourage him to talk with his daughter about “what matters most,” giving them the Conversation Starter Kit.
Best practice about prognosis

- People want information in a variety of ways
- Often quantitative is preferred
  - Draw on both models and experience
  - Ranges are best, rather than averages
  - Avoid “risk of survival/death,” instead say “Out of 100 people in similar situations, 35 will die within five years, 65 will survive”
- Sometimes qualitative is sufficient
  - “I worry that, because [the serious illness] has progressed despite all the [treatments] we have to offer, that time may be short.”

Gagne Index

- Population: Community-dwelling adults aged 65 years and older
- Outcome: All cause 1 year mortality
- Scroll to the bottom for more detailed information

As illustrated by the graphic below, out of 100 community-dwelling adults aged 65 years and older with similar answers, 20 will die (shaded) and 80 will survive (un-shaded) over the next year.

Risk calculators cannot predict the future for any one individual. Risk calculators give an estimate of how many people with similar risk factors will live and die, but they cannot identify who will live and who will die.
Mr. Smith

- In 2 weeks, Mr. Smith returns, his daughter joins by FaceTime. They used the Starter Kit and he shares some of “what matters most” to him.
- The clinician then asks about Mr. Smith’s understanding of his situation, reviews the status of his illnesses, and asks him to explain back his understanding. Once that is done, two transitions are made:
- “I’m worried about you getting sick again.” Mr. Smith and his daughter are also worried but hopeful. Mr. Smith’s prognosis is shared, the clinician responds to emotions, and treatment options are discussed.
- “Would it be ok if we made a plan in case things don’t go the way we’d like?” Anticipated emergencies are discussed, and the clinician makes an informed recommendation about life sustaining treatment. Mr. Smith and his daughter leave grateful and trusting his clinician has his best interests at heart and will respect his wishes.
Overview

Building reliability
- System
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- Individual
  - Improving conversations
Connect

- Factors: socioeconomic, ethnic, cultural, spiritual, language
  - Vulnerable populations
  - Death as a taboo topic
  - Unrecognized traditions
  - Clinicians don’t want to “take away hope”

- Building reliability for all
  - System
  - Individual

- Respect, humility, curiosity
Connect

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