SERIOUS ILLNESS CONVERSATIONS

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DISCLOSURE

- No relevant financial relationships
- Parts of this presentation and the Allina Serious Illness Care Program are based on work by Ariadne Labs, a joint center for health systems innovation at Brigham and Women's Hospital and Harvard T.H. Chan School of Public Health

OBJECTIVES

1. Articulate elements of a Serious Illness Conversation and the benefits
2. Identify seriously ill patients who would benefit from a serious illness conversation
3. Locate patient's goals and preferences in the Advance Care Planning Navigator

Case

- 52 year old salesperson
- Stage IV pancreatic cancer
- Receiving chemotherapy; 3 months of chemotherapy so far
- Metastases shrinking on CT scan
- Spouse very involved; 1 adult son
- Patient returned to work 4 weeks ago

What do you think the patient's prognosis is?

What do you expect the patient's medical course will be over the coming year?

What would help the patient most at this time?

What is serious illness communication?

- Conversations about expected course of a serious illness and patient's goals, values, and priorities that can inform treatment decisions
- Type of advance care planning but NOT a "code status" discussion
- **Not necessarily an end-of-life** discussion -- rather, aim is to prepare patients and families for an uncertain future

We need to remind ourselves

"Death is not a medical event. It is a personal and family story of profound choices, of momentous words, and telling silences."

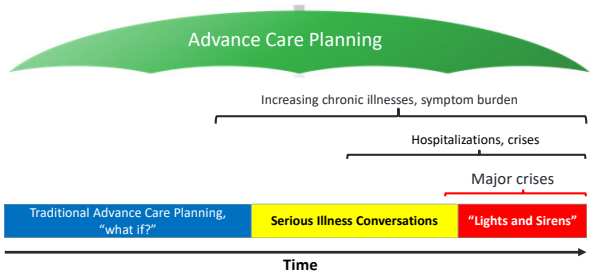
Dr. Steven Miles
Professor Emeritus
U of MN Center for Bioethics

Communication is a skill we can all learn

"Despite our very human impulse to run away from frightening discussions, ultimately communication is the basis of everything sacred in the doctor-patient relationship: trust, vulnerability, honesty, compassion. [It is] a skill we can all learn."

Dr. Sunita Puri
That Good Night: Life and Medicine in the Eleventh Hour (2019)

Moving Serious Illness Conversations upstream



Why is this important for patients?

- Leads to care that is concordant with patient's goals and priorities
- The gift of time – focus is on how patients want to **live**
- Better quality of life
- Fewer hospitalizations
  - Vast majority of patients want to spend final days at home
  - Currently:
    - 25-39% die in a hospital
    - 70% are hospitalized in last 90 days
    - 29% are in ICU in last 30 days

Benefits for providers

- Increased understanding of patient's preferences and goals
  - Subsequent visits can build on that common understanding
- Improved goal-concordant care of the patient
- Decreased sense of moral distress
- Increased professional satisfaction

What's wrong with Advance Care Planning?

- 2018 review of 80 systematic reviews of 1600 articles found no evidence that ACP improved end-of-life care
- 2020 review of 62 articles: no association of ACP with subsequent ED visits, hospitalizations, and critical care
- Why?
  - Too difficult for people to articulate values and goals and treatments that align with those goals in hypothetical future scenarios
  - Patient preferences change over time
  - ACPs difficult to find in chart
  - Clinicians don't always read documents and integrate into conversation with surrogates

Alternative?

- Maybe ACP is necessary for good end-of-life care but not sufficient?
- Problem of unintended consequences:
  - Institutional incentives to promote ACP completion can detract from other initiatives
  - Patients leave ACP sessions with serious misconceptions about life-sustaining treatments
  - Presence of an ACP can inhibit current discussions about goals of care
    - This has occurred during the COVID-19 pandemic
- Proposal:
  - Train clinicians to have high-quality discussion when actual (not hypothetical) medical decisions must be made
  - Prepare patients and families to engage in these discussions

End-of-life discussions among patients with advanced cancer

Not universal
- 73% (1569 of 2155) with stage IV lung or colon cancer had EOL discussion
- Only 49% of the discussions were with a medical oncologist

Late
- First discussion took place a median of 33 days before death
- 55% of the discussions occurred in the hospital – in a crisis -- rather than during stable outpatient care

Limited in scope
- Often focused on end-of-life procedures rather than what matters most to patients

Not well documented
- Medical oncologists documented end-of-life care discussions with only 27% of their patients (493 of 1823)

Mack, JW, et al. End-of-Life care discussions among patients with advanced cancer: a cohort study. *Ann Intern Med.* 2012;156(3):204-210

Absent, late, and poor-quality communication contributes to:

- Avoidable suffering for patients and families
- Overly aggressive, lower-quality care that may not align with patient goals

Why aren't we having these conversations more often?

Barriers

Provider
- Time
- Uncertainty about prognosis and fear of dashing hopes
- 68% not trained to have these conversations
- Assumption – in the part of the provider as well as the patient and family – that there is always more that can be done
- Desire to please the family – e.g., the daughter wants to fight harder than the patient
- Competing interests – sharing my honest assessment of prognosis can drastically hurt my patient satisfaction scores

Medical system
- Defaults to aggressive care for the terminally ill

Patient
- "Fighter" mentality
- Deference to specialist who offers another intervention

Pitfalls in communication with patients with advanced cancer

- **Discussing serious news**
  - Proceeding without assessing what the patient already knows
  - Using medical jargon
  - Blocking or overlooking emotional reactions to serious news
- **Dealing with emotions**
  - Talking while patient is absorbing
  - Missing emotion cues and not responding to emotion explicitly
  - Redirecting away from sadness
- **Eliciting values**
  - Skipping values to get to decisions
  - Overlooking cultural differences – value of anticancer treatments over other issues (spirituality, role responsibilities)

Back, AL. Patient-clinician communication issues in palliative care for patients with advanced cancer. *Am Soc Clin Oncol* 2020;38(9):866-877

17

Pitfalls in communication with patients with advanced cancer

- **Preparing for the future**
  - Avoiding discussions about dying or treatment failure
  - Withholding information about survival even when a patient requests it explicitly
  - Assuming that patient willingness to discuss the future will not change
- **Making decisions about goals of care**
  - Emphasizing extreme outliers in survival benefit
  - Omitting downsides of chemotherapy near the end of life
  - Not offering the option of stopping treatment

Back, AL. Patient-clinician communication issues in palliative care for patients with advanced cancer. *Am Soc Clin Oncol* 2020;38(9):866-877

18

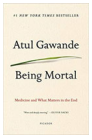
Serious Illness Care Program

- **Communication tools**
  - Serious Illness Conversation Guide
- **Training programs**
- **System changes**
  - Patient identification to trigger conversations
    - The new Serious Illness Filter
  - Documentation in a consistent findable place in the EMR
    - The new ACP (Advance Care Planning) Navigator
  - Serious Illness Standard Work

Demonstration of conversation

https://youtu.be/bu7V-k9tvL8

Serious Illness Conversation Guide



- Framework for BEST communication practices in the setting of serious illness
- Like the Surgery Checklist, the guide:
  - Ensures completion necessary tasks during complex, stressful situations
  - Reduces clinician and patient anxiety
- Developed with feedback from patients, families, and clinicians by:
  - Ariadne Labs, a research center at Brigham and Women's Hospital and the Harvard School of Public Health
  - Dr. Atul Gawande is the founding executive director
- Used and tested in settings world-wide

Guide

- **Effective and efficient** tool
- Wording and sequence of the questions carefully crafted to **foster alignment** with the patient.
- Questions **can be read verbatim** – they work.

Overall arc of the conversation

1. **Set up the conversation – explain rationale**
2. **Assess patient's illness understanding and information preferences**
3. **Share prognosis**
4. **Explore what matters most**
   - Patient's goals and priorities in light of that prognosis
   - Trade-offs they are willing or not willing to make
5. **Close with recommendation grounded in the patient's values and priorities**

Prognosis

- 50% of patients lived longer and 50% lived shorter than oncologists' estimate of expected survival time
- **But** 25% of patients died within half their expected survival and 10% died within a quarter of their expected survival

JAMA Oncology editorial March 14, 2019 – original data from J Clinical Oncology 2013 and British J Cancer 2006

Communicating prognosis does not take away hope

- ***When well done*** -- does not take away hope, cause depression, increase anxiety, or harm the relationship with the clinician.
- In contrast, some evidence that it supports hope and peace of mind, even when prognosis is poor.

Training

- Regularly scheduled 4-hour classes available a couple times a month
- Small groups (5-8 ideal)
- Includes opportunity to practice using the Conversation Guide and become more comfortable using it
- CME credit

Patient experiences – from hospitalist comments

- "My favorite experience was with a very kindhearted Indigenous American patient. The conversation went well, and though slow and deliberate, it took [just] 25 minutes. At the end she told me that she was used to doctors telling her what to do, so she was appreciative of being asked what she wanted out of her healthcare."
- "I think for me the most significant and telling moment was the patient (who had advanced liver cirrhosis requiring weekly paracentesis) was totally crestfallen and surprised when she was told she had a 'serious illness'."
- "Patient with chronic kidney disease who had no idea she was nearing dialysis and was very grateful that I had brought it up. She and her husband thanked me every day afterward for discussing it with them."

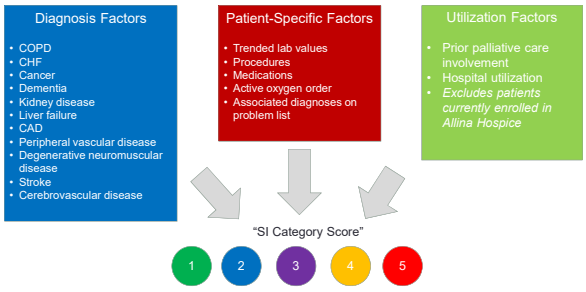
Provider experiences

- "We're doing what we love to do. It's why we went into medicine."
- "I love it that this gives me dedicated time and new tools. The Guide helps keep the visit organized. I feel more equipped and I've gotten to know my patients better. Not talking in a crisis is ideal."
- "My patient felt more empowered after our conversation."
- "My patients' families have appreciated the conversation maybe even more than the patient."

Making SI conversations part of routine care at AHCI

- Train all providers, nurse navigators, and social worker
- Identify patients who would benefit from conversation
- Schedule an appointment
- Nurse navigator or social worker follows up with patient after conversation

Serious Illness Filter



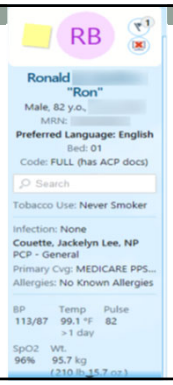
When to have these conversations

- **At time of diagnosis**
  - All patients with late-stage cancer or with expected survival time of 2 years or less
  - Patients learn that communication about their prognosis and their goals and values is an integral part of their care
- **All Category 5 patients. Consider Category 3-4 patients.**
- **Recurrence, remission, or change in patient's goals**
- **Patient's perception of burden of treatment side effects greater than benefits**

Kiely BE, et al. The median informs the message: accuracy of individualized scenarios for survival time based on oncologists' estimates. *J Clin Oncol* 2013;31(28):3565-3571

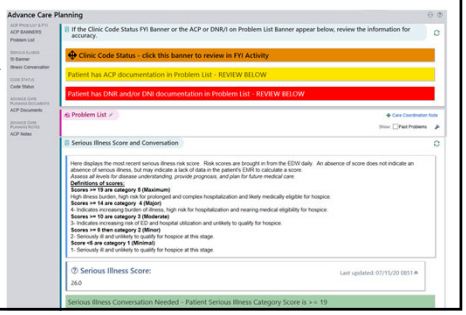
Documenting the conversation

Access the new ACP Navigator by clicking on "Code" status on the patient Storyboard

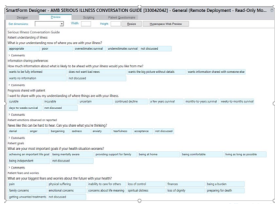


ACP Navigator: source of truth

Click on "Illness Conversation" to get to template

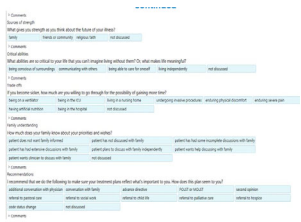


Serious Illness Conversation SmartForm



Provides possible patient answers, as well as option to free text their responses

This template includes the exact questions in the Guide



Final reflection

"We've been wrong about what our job is in medicine. We think our job is to ensure health and survival.

But really it is *larger* than that. It is to enable well-being. And well-being is about the reasons one wishes to be alive."

Dr. Atul Gawande

Billing

Conversation is billed like a procedure (type "ACP" into order box and sign "order" using ACP as "diagnosis")

- **99497** (1.5 RVUs)
  - must spend 16 minutes of first 30 minutes on ACP
- **99498** (1.4 RVUs)
  - For each additional 30 minutes
  - Enter in addition to 99497

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