Becoming a “Conversation Ready” Organization

Session 4: Respect - Meeting people where they are as illness advances

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Kate Lally
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Angela G. Zambeaux, Senior Project Manager, Institute for Healthcare Improvement, has managed a wide variety of IHI projects, including a project funded by the US Department of Health and Human Services that partnered with the design and innovation consulting firm IDEO around shared decision-making and patient-centered outcomes research; the STAAR (STate Action to Reduce Avoidable Rehospitalizations) initiative; virtual programming for office practices; and in-depth quality and safety assessments for various hospitals and hospital systems. Prior to joining IHI, Ms. Zambeaux provided project management support to a small accounting firm and spent a year in France teaching English to elementary school students.
Kate Lally, MD, FACP, Chief of Palliative Care, Care New England Health System, also serves as Medical Director at Integra Accountable Care Organization and Hospice Medical Director of Care New England VNA Hospice. At Care New England, she developed a system-wide comprehensive, interdisciplinary palliative care program that has expanded from the hospital into the community. Dr. Lally spearheaded Care New England’s role as a Pioneer Sponsor in the Institute for Healthcare Improvement’s Conversation Ready initiative and helped integrate Conversation Ready principles into the health system’s palliative care program. She has served on the faculty of the IHI since 2013, and as a result has developed and led a number of on-line and in-person educational initiatives for both national and international audiences. As a result of her work, she has received numerous awards including “Top Doc” in RI monthly, Providence Business News “40 under 40” and was named an “Inspiring Hospice and Palliative Medicine Leader Under 40” by the American Academy of Hospice and Palliative Medicine. She is a graduate of Yale School of Medicine and did her post-graduate training in Internal Medicine at the Hospital of the University of Pennsylvania. She currently serves as an Assistant Professor of Medicine (Clinical) at the Warren Alpert Medical School of Brown University.
Laufe Sokol-Hessner, MD, is a hospitalist and the Associate Director of Inpatient Quality at Beth Israel Deaconess Medical Center (BIDMC) in Boston. He has worked in southern Africa on multiple occasions, completed medical school and residency at the University of Pennsylvania in Philadelphia, and worked as an attending physician at the University of Washington Medical Center in Seattle before joining BIDMC. On the wards, his work includes collaborating as a member of interdisciplinary teams of health care providers, coaching medical students and residents as they develop their communication skills, and caring for a broad variety of patients and their families. In his quality improvement role he leads several projects, including Conversation Ready at BIDMC.
Webinar Series Objectives

At the conclusion of this webinar series, participants will be able to:

- Articulate the vision and mission of The Conversation Project and different ways to approach end-of-life care conversations.
- Describe strategies that have worked for pioneer organizations to engage patients and families in discussions to understand what matters most to them at the end-of-life.
- Explain ideas for reliably stewarding this information across the health care system, including strategies for working with electronic health records.
- Teach ways to engage communities that help to activate the public in having these conversations in advance of a potential medical crisis.
- Test methods to help staff engage in this work personally before exemplifying it for their patients.
- Describe changes to CMS reimbursement policies for advanced care planning conversations.
Today’s Agenda

- Introductions
- Debrief Sessions 3-4 Actions
- *Respect: Meeting people where they are as illness advances*
- Action Period Assignment
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 shared goals of care
4. **Exemplify** this work in our own lives so that we understand the benefits and challenges
5. **Connect** in a manner that is culturally and individually respectful of each patient
Schedule of Calls

Session 1 – The Conversation Project: Reaching people where they live, work, and pray
Date: Tuesday, May 23, 2017, 2:00 PM-3:00 PM Eastern Time

Session 2 – Engage: Moving from passive to proactive
Date: Tuesday, June 6, 2017, 2:00 PM-3:00 PM Eastern Time

Session 3 – Steward: Achieving the reliability of allergy information
Date: Tuesday, June 20, 2017, 2:00 PM-3:00 PM Eastern Time

Session 4 – Respect: Meeting people where they are as illness advances
Date: Tuesday, July 11, 2016, 2:00 PM-3:00 PM Eastern Time

Session 5 – The Exemplify Principle in Action/ Connecting In a Culturally Respectful Manner
Date: Tuesday, July 25, 2:00 PM-3:00 PM Eastern Time

Session 6 – CMS Reimbursement
Date: Tuesday, August 8, 2:00 PM-3:00 PM Eastern Time
Suggested Action (spans sessions 3 and 4)

Review the charts of the last 20 patients* who died in your setting. As you review the charts, note evidence of the following:

- Advance directive documents are accessible and can be understood by the care team (i.e., not just a “Yes/No” notation that the patient has an advance directive);
- Documentation of provider and patient conversation(s) — or conversation(s) with a surrogate decision maker, if the patient is not able to participate — about “What matters?” to the patient regarding end-of-life care wishes;
- Location of death;
- Whether patient received life-sustaining treatment;
- A few details about the patient’s medical history and situation immediately prior to death; and
- The presence of indicators about whether the care the patient received was aligned with their documented end-of-life care wishes.

Consider including representatives from the involved clinical services in the review, to understand their perspectives on the care provided and to engage them in the work.

* We recommend 20 for a fuller picture of your system but if that is a stopper, then do 10.
To share today:

Briefly document two stories gleaned from the review that illustrate current end-of-life care processes (to help build will among colleagues and create a clearer picture of reasons to engage in work).

For example:

- Mr. S had a note in his patient chart that an advance directive existed, but it was not accessible in the patient chart. There was no documentation of discussions with providers about end-of-life care goals, and the care team was not able to determine alignment of care goals and Mr. S’s end-of-life care wishes.

- Ms. W had an accessible advance directive and detailed notes about end-of-life care goals in her patient record, and she was transferred to an inpatient hospice unit in apparent alignment with her wishes.

Information from the review can be used to guide team conversations about setting an aim, selecting a subpopulation, and identifying the best location for pilot testing. Additionally, this information can help build will when discussing work with colleagues.
The Respect Principle

Meeting people where they are as illness advances

Kate Lally, MD, FACP
Laufe Sokol-Hessner, MD
At Retaining Hope Health Care there is a disconnect between anything that is known about patient wishes and their actual care leading up to their deaths. Still not wanting to take away hope and not wanting to declare that the end is nigh, care planning conversations do not surface the gravity of patient situations and opportunities to direct care differently. Families expressed being surprised afterwards that death was so close when they still thought treatment would be effective.
At Reliability Health Care, early engagement and reliable stewarding means that there is confidence that what has mattered most to patients over time is known and that this information is accessible and ready to be confirmed and adapted to current circumstances as patients get closer to death. Patients and their loved ones are not caught off guard about the gravity of their illnesses and have an opportunity to take actions that have meaning to them prior to the end of their lives.
What does it mean to respect patient wishes?

Consider three core conversation topics:
- Information about diagnoses, prognoses and treatments
- “What matters most” to the patient
- Shared decision making

What does Reliability get right?
- Conversations about serious illnesses and poor prognoses
  - Recognition that hope is not inconsistent with developing a plan
- Early engagement and stewarding about “what matters most”
- Engagement in shared decision making
  - Care consistent with “what matters most” to patients
- Doing it the right way, each time, with every patient
Underlying concepts from Chittenden et al., “Discussing Resuscitation Preferences with Patients: Challenges and Rewards,” JHM 2006
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Clinician

Patient/family

- Assumptions about “what matters most”
- Paternalism

Unilateral decision
Offer “menus” and overwhelming detail

No guidance

“patient autonomy”

Underlying concepts from Chittenden et al., “Discussing Resuscitation Preferences with Patients: Challenges and Rewards,” JHM 2006
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“Co-production” through shared decision making

Clinician

Use clinical judgment when discussing treatments & side effects

Patient/family

Incorporate the patient’s goals, values, preferences
When a doctor and patient disagree about care at the end of life

By Ravi Parikh  April 18

Sometimes, doctors and patients disagree about end-of-life care. I know, because it happened with me.

Not long ago, a frail-looking elderly patient appeared at my cardiac health clinic with a file full of hospitalizations stemming from a heart attack years before. He’d had three coronary stents put in, had had heart bypass surgery and was unable to walk for more than a block due to chest pain. I saw that a previous doctor had written “DNR” — do not resuscitate — in his chart, so I asked him to confirm his wishes.

No, he said, to my surprise. He actually wanted to be a “full code” — meaning that chest compressions, shocks and intubation were to be used if necessary to keep him alive.
It is about providing care consistent with wishes…

- Mrs. A is a woman with recurrent cervical cancer.
- She struggled with initial trials of chemotherapy and became very symptomatic.
- She understands that her cancer is no longer curable.
- She no longer wants chemo, feels that she wants to focus on quality of life over length of life.
- Her goal is to stay home and go on to hospice.
- She dies at home 3 months later.

- Mrs. B is a woman with recurrent cervical cancer.
- She struggled with initial trials of chemotherapy and became very symptomatic.
- She understands that her cancer is no longer curable.
- Her daughter is getting married in 3 months and she wants to do everything to make it to her daughter’s wedding.
- She undergoes chemotherapy until the week before her daughter’s wedding.
- She goes on hospice and dies 2 weeks after her daughter’s wedding.
What are the ways in which this goes wrong?

- Failure to collect information about “what matters most” and the goals of care
- Health care professionals insert their own perspectives and values, usually unconsciously and unintentionally
- Lack of confidence that informed decisions have been made
  - Sometimes a lack of shared decision making
  - Sometimes just a sign of poor team communication
  - Either way can lead to moral distress

Dzeng et al., “Moral Distress Amongst American Physician Trainees Regarding Futile Treatments at the End of Life: A Qualitative Study,” JGIM 2015
Pause

Questions? Comments?
3 cases exploring Respect

1. When the patient cannot tell us “what matters most”
2. When prognosis is uncertain
3. When it’s not clear that care is consistent with “what matters most”
Case 1 – Mrs. Jones

- Had a large stroke several months before her hospitalization
- Difficulty eating and with caring for herself
- Daughter was her primary caretaker
- Mrs. Jones found at home minimally responsive
- Admitted to hospital with large stroke, unable to speak for herself
Case 1 – Mrs. Jones

- Doctors considering feeding tube vs comfort care
- Daughter is tearful and anxious making decisions
- “I don’t know what she would want, we never talked about it”
- How do we identify Mrs. Jones’ wishes to make sure we are respecting them?
How do we know we are respecting Mrs. Jones’ wishes?

- In the absence of stated preferences, we can infer things from different data sources:
  - Gather info about how she lived her life
  - What was important to her?
  - What did she tell her daughter about her quality of life?
  - What were her experiences with her parents’ deaths?

- How would her prognosis affect what mattered most to her?
Suggested language for Mrs. Jones’ daughter

- “What was your mother like when she was well? If we look back a couple of years ago, what type of things did she like to do?”
- “How did she feel about her quality of life after her last stroke?”
- “She has had a major stroke. If we place a feeding tube she will likely need to go to a nursing home for 24 hour care. How would she feel about that?”
3 cases exploring Respect

1. When the patient cannot tell us “what matters most”
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Case 2 – Mrs. Smith

- Mrs. Smith is a 71 year woman with COPD
- Has advance directive stating DNR/DNI
- She gets very ill and goes to the hospital
- Placed on BIPAP
- Physicians feel she has a good chance of recovering with a short trial of intubation
How do we make sure we are respecting Mrs. Smith’s wishes?

- We need to understand her concerns and fears around her illness and aggressive treatments.
- Would she have been willing to try it for a short period of time?
  - Time limited trials
  - Viewing prognosis as continuously evolving
- Set a future date to re-address prognosis and goals if she does go on a ventilator.
“Your mother said she would not want to be on a ventilator. That is certainly understandable. What were her concerns about the ventilator?”

“Was she afraid of being on the ventilator for a long period of time?”

“I think we could improve her breathing if she went on the ventilator for a few days. Would she be willing to do that?”

“If she is not improved in 3-4 days we should discuss whether we should continue or shift our focus to comfort at that time”
3 cases exploring Respect

1. When the patient cannot tell us “what matters most”
2. When prognosis is uncertain
3. When it’s not clear that care is consistent with “what matters most”
Case 3 – Mrs. Lynch

- 78yo woman with COPD and lung cancer
- Declining for several months
- Now mostly house bound, oxygen dependent
- Wants to spend her remaining time with family and avoid returning to the hospital again
- Advance care planning has never been attempted
- Develops pneumonia
Case 3 – Mrs. Lynch

Without advance care planning

- Poor prognosis not acknowledged, even when patient asked
- Admitted to the ICU with pneumonia and delirium, intubated
- Unclear who should be her “voice,” contributing to family disagreements
- Difficult situation, with loss and sadness, anger, confusion and moral distress
- Develops complications, doesn’t regain capacity, dies in the hospital
- Doesn’t complete her life in the ways that mattered most to her
- Complicated bereavement

With advance care planning

- Health care professionals would have talked about her prognosis in patient-centered ways and aligned around hope, but made a plan in case things didn’t go well
  - Surrogate decision maker
  - “What matters most”
  - Enrolls in hospice
  - POLST/MOLST
- Pneumonia would occur, and she’d be given treatment consistent with her goals
- It’d be a difficult situation, with loss and sadness, but everyone would have confidence in the decisions that had been made
- She would have died surrounded by family and in the ways that mattered most to her
- Improved bereavement
Mrs. Lynch (and her family) have suffered preventable harm

- If we agree that...
  - It is our responsibility – as health care professionals – to preserve patient autonomy and ensure patients are always given the opportunity to make informed decisions
  - And that in the context of serious illness, advance care planning is the way of ensuring informed decisions are being made

- Then...
  - What keeps us from “seeing” this as preventable harm?
  - What will it take to generate consensus that the lack of appropriate advance care planning for seriously ill patients is poor quality care?
Consider another story of preventable harm…

- Central-line associated bloodstream infections (CLABSIs)
  - Used to be that “they just happen as part of care”
  - Innovation led to a bundle of discrete interventions to prevent them
  - Now reliable use of the bundle is considered the standard of care – the harm is largely preventable

- What will it take to make these aspects of advance care planning the standard of care?
  - Identifying a surrogate decision maker
  - Having conversations
    - Sharing the diagnosis, prognosis and treatment options
    - Understanding “what matters most”
    - Shared decision making
  - Appropriately using POLST-paradigm forms
Engaging in the “practice of respect”

- Capturing preventable emotional harm events, treating them with the same rigor with which we treat physical harm events
  - Assessing, categorizing, understanding, discussing

- Learning about the importance of a reliable “practice of respect” for seriously ill patients from individual cases/stories:
  - Lack of indicated advance care planning
  - Failure to appropriately involve surrogate
  - Problems discussing serious news
  - Lack of informed decision making
  - Failure to anticipate future emergencies
  - Problems managing limitations on life-sustaining treatment

Pause

- Questions? Comments?
Suggested Actions

- Review one of the following Ethnogeriatrics modules on https://geriatrics.stanford.edu/
  - African-American
  - American Indian
  - Asian Indian
  - Chinese
  - Filipino
  - Native Hawaiian and Pacific Islander
  - Hispanic/Latino
  - Japanese
  - Korean
  - Pakistani
  - Vietnamese

- Identify at least one story in your own practice where culture competency fell through the cracks and less than optimal care was provided at the end-of-life
Session 5

The Exemplify Principle in Action/ Connecting In a Culturally Respectful Manner

Rev. Rosemary Lloyd, BSN, MDiv
Advisor to the Faith-Based Community,
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Tuesday, July 25, 2-3 PM Eastern
Thank You!

Please let us know if you have any questions or feedback following today’s webinar.