Respecting Wishes: Lessons from Conversation Ready

The Conversation Project

April 17, 2018
WebEx Quick Reference

Welcome to today’s session!

Please use Chat to “All Participants” for questions

For technology issues only, please Chat to “Host”

WebEx Technical Support: 866-569-3239

Dial-in Info: Audio / Audio Conference (in menu)

Raise your hand

Select chat recipient

Enter Text
Ice Breaker Question

Type into the chat box your response to the following:

What type of organization/institution are you affiliated with?

Make sure you send your message to “All Participants.”
Where are you located on the map?
The Conversation Project Field Team

Patty Webster
Improvement Advisor

Naomi Fedna
Project Coordinator
Call agenda

- TCP Updates/New Resources
- Framing
- Working across Boundaries to be Conversation Ready
- Questions and Discussion
- Wrap up
## Upcoming Community Calls

The next Conversation Project Community Call will take place on:

**Wednesday, May 15th, 3:00-4:30 PM ET**

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TCP Updates: New Resources

- TCP standard slide deck and end-of-event evaluation - Spanish versions [https://theconversationproject.org/resources/community](https://theconversationproject.org/resources/community)
- Top Tools Page
TCP Conversation Champions Map

Search, connect/network and learn together

https://theconversationproject.org/get-involved
TCP Community REMINDER

Quarterly **Community Activity Survey** is open until Friday April 26\(^{th}\)!

[https://www.surveymonkey.com/r/DP325TF](https://www.surveymonkey.com/r/DP325TF)
A public engagement campaign dedicated to assure that everyone’s wishes for end-of-life care are expressed and respected.
The Conversation Continuum

End of Life Wishes

Healthy

Living with Chronic Illness

Approaching End of Life

Expressed

Spoken

Documented

Respected

Accessed

Implemented
What Matters TO Me?

What’s the Matter with Me?

As Well As

Public Awareness Community Engagement

Health Systems Transformation
Kelly McCutcheon Adams, MSW, LICSW, is a Senior Director at the Institute for Healthcare Improvement, where she focuses on critical care and end-of-life care. She also teaches the IHI Breakthrough Series College regarding running successful collaboratives. She is an experienced medical social worker with experience in emergency department, ICU, nursing home, sub-acute rehabilitation, and hospice settings. Ms. McCutcheon Adams served on the faculty of the U.S. Department of Health and Human Services Organ Donation and Transplantation Collaboratives as well as on the faculty of the Gift of Life Institute in Philadelphia. She has a BA in political science from Wellesley College and an MSW from Boston College.
Working Across Boundaries to be Conversation Ready

Kelly McCutcheon Adams, LICSW
"...being a physician involves much more than handing out diagnoses and treatment; it involves playing a role in some of the most intimate decisions of a patient’s life. This requires a considerable amount of human delicacy and judgment..." - Oliver Sacks
History of the work: 2012-Present

- The Conversation Project
- Pioneer Sponsors
- First Collaborative
- Seminar, White Paper, Expeditions
- Howard County (MD) and Massachusetts Collaboratives
- Just published: Conversation Ready White Paper
- Coming VERY soon: Conversation Ready Toolkit
There is a gap

More than **9 in 10** Americans think it’s important to talk about their loved ones’ and their own wishes for end-of-life care.

**Nationally...**

- **32%** have discussed what they want when it comes to their end of life care with their loved ones.

**In one state...**

- **13%** had a conversation with a health care provider about end-of-life care wishes.

- **27%** of patients with a *serious health condition* had a conversation with a health care provider about their end-of-life care wishes.

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Constitution Project Survey, 2018
Massachusetts Coalition for Serious Illness Care Survey, 2018
The gap matters to patients & families

Goal discordant care can cause harm...

- Exposes patients to the risks of treatments they don’t want
  - Or deprives them of the benefits of treatments they do want
- May cause patients (and their families) to lose opportunities to have spent their time differently
- Fosters distrust of the involved health professionals and organization when patients realize there was a better alternative for them
- May make them less willing to return or to recommend
- At worst → an undignified death
Clinicians decide
No patient input

Patient decides
No clinician input

The Pendulum of Decision-Making
Conversation Ready Principles
Conversation Ready Principles

Exemplify → Connect → Engage → Steward → Respect
Conversation Ready Principles

1. **Exemplify** this work in our own lives so that we fully understand the benefits and challenges

2. **Connect** with patients and families in a culturally and individually respectful manner

3. **Engage** with our patients and families to understand what matters most to them at the end of life

4. **Steward** this information as reliably as we do allergy information

5. **Respect** people’s wishes for care at the end of life by partnering to develop a patient-centered plan of care
Exemplify: Walking the walk

- I Voted
- American Red Cross
  BE NICE TO ME, I GAVE BLOOD TODAY!
"Talk Turkey" Encourages End-of-Life Discussions

Published: 11/21/2013 9:00:00 AM

As families around the country gather for Thanksgiving, BIDMC’s Department of Social Work and Ethics Support Service will hold its annual “Talk Turkey” campaign to educate staff, patients and visitors about the importance of health care proxies on Monday, Nov. 25 and Tuesday, Nov. 26.

Health care proxy forms in multiple languages and other advance directives materials will be distributed at the east and west campus cafeterias, as well as the West Clinical Center and Carl J. Shapiro Clinical Center lobbies.
“...in addition to our community outreach efforts, we have started to engage med students, residents, nurses and nursing students, case managers, and social workers. Fortunately, we have a wonderful [palliative care] doctor on our outreach team, she has... been a huge asset to the team... [connecting] me with ... different departments throughout the hospital to schedule presentations... we’ve received a lot of positive feedback in doing this, and have even been asked to do 2-3 part series for the different groups. It’s very encouraging!”
Connect: Finding cultural humility
Clergy at the Intersection of Life & Death

“Henry Ford Health System has worked for decades with the faith community, …but before the IHI Conversation Ready program challenged us, we had never brought the two communities together.”

- Over 200 clergy and clinician dialogue partners
- They post resources for faith communities [http://www.henryford.com/body.cfm?id=59375](http://www.henryford.com/body.cfm?id=59375)
- Tailor advance care planning outreach to underserved or underrepresented populations
Other Connect Examples:

- Contra Costa Interpreter Training
- Boston Senior Home Care – work with Chinese elders in housing communities
An amazing resource from Stanford

Ethnogeriatrics modules

- African-American
- American Indian
- Asian Indian
- Chinese
- Filipino
- Native Hawaiian and Pacific Islander
- Hispanic/Latino
- Japanese
- Korean
- Pakistani
- Vietnamese
Engage:
Moving from reactive to proactive
New Palliative care program experienced explosive growth
About 70% were for goals of care
Needed a way to engage more patients with limited resources
RN very skilled in having goals of care conversation
  - Re-labelled her “Conversation Nurse”

How the Conversation Nurse role took off

- Contacted directly by MDs to have goals of care conversations
- Now broad acceptance by providers and patients
- Hospital sees Palliative Care as a team-based program
- Have expanded to three nurses
How to Change the Culture

- Document what you hear when you ask
  - “What Matters Most to You?”
  - Examples:
    - I want to die at home.
    - I want to see my sister before I go.
    - I want to continue all treatment until it is clear that I cannot communicate with my family.
Steward: The Allergy Analogy
Advance care planning as a process

Provider A
- Usually outpatient
- Forms a relationship
- **Reach and Record**:
  - Health care proxy
  - Conversations
  - MOLST

Provider B
- Often inpatient
- Often no preceding relationship
- **Retrieve** data to help ensure care is congruent with wishes → **Respect**

Nears the end of life
Active dying
Death

Patient establishes care

Serious illness
Organ failure
Terminal illness
Frailty

Allergy analogy

Virginia Mason Medical Center’s Electronic Medical Record
Respect: The real outcome
Don’t Panic – It’s OK: A Letter to my Family

If you are faced with a decision that you’re not ready for,
It’s ok
I’ll try to let you know what I would want for various circumstances,
But if you come to something we haven’t anticipated,
It’s ok
And if you come to a decision point and what you decide results in my death,
It’s ok.
You don’t need to worry that you’ve caused my death – you haven’t –
I will die because of my illness or my body failing or whatever.
You don’t need to feel responsible.
Forgiveness is not required,
But if you feel bad / responsible / guilty,
First of all don’t and second of all,
You are loved and forgiven.

If you’re faced with a snap decision, don’t panic --
Choose comfort,
Choose home,
Choose less intervention,
Choose to be together, at my side, holding my hand,
Singing, laughing, loving, celebrating, and carrying on.
I will keep loving you and watching you and being proud of you.
A starting place: Death Chart Review process

- One of the simplest ways for organizations to get started learning about their systems and thereby better focus their efforts is to perform a Death Chart Review, which is done by noting the following items for each of the last 10 to 20 patients who died in a relevant setting of care:
  - Location of death, the circumstances of the death (traumatic, sudden, prolonged, expected, etc.), and the presence of any serious illnesses (cancer, dementia, heart failure, etc.)
  - Documentation of legally authorized surrogate medical decision maker (e.g., durable power of attorney for healthcare, health care proxy, etc.)
  - Evidence of other advance directives (e.g., living wills, and not that they were just noted to exist, but that they could be accessed and understood)
  - Documentation of “what matters most” to the patient
  - Documentation of provider and patient conversation(s) about end-of-life care wishes (or with surrogate decision maker, if patient not able to participate)
  - Evidence of POLST-paradigm type form(s)
Thank you
Q&A and Discussion
# Monthly Community Calls

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TCP Health Care Resources

- **White Paper:** Conversation Ready: A Framework for Improving End-of-Life Care (2nd edition)
- **Free course/call series**
- **Resources on cultural and ethnic considerations**

https://theconversationproject.org/resources/healthcare/
Related article/videos

- Conversation Ready’s Kate Lally, MD: Having the Conversation I Encourage Others to Have
  https://jamanetwork.com/journals/jama/fullarticle/2730118?resultClick=1

- David Wood, MD, CMO Beaumont Health, MI shares challenging experience he faced as the surrogate decision maker for his father at the end of life
  https://theconversationproject.org/When-wishes-are-not-respected-at-end-of-life

- Lachlan Forrow, MD, asks Dolly Baker simply and deeply: “what would make today a good day for you?”
  https://theconversationproject.org/tcp-blog/the-doctor-and-the-jazz-singer/
Write a Letter to Your Loved One

- Write a letter to your loved one(s) about what matters most to you and email your letter to conversationproject@ihi.org
We want your feedback!

After this call you will be redirected to a Survey Monkey form.

Please take a few moments to answer questions that will ask you to rate the overall effectiveness of this call.

THANK YOU!
Thanks and appreciation

The John A. Hartford Foundation
Dedicated to Improving the Care of Older Adults