

Engaging Residents and Families: Hearing the Voice and Offering the Choice

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Objectives:

- ▶ Reflect on the impact of communication on patient care
- ▶ Describe the benefits of serious illness conversations for patients, families, and clinicians
- ▶ Identify key elements of a serious illness conversation
- ▶ List tools to help guide difficult conversations
- ▶ Identify strategies to engage residents and families in difficult conversations
- ▶ Transform conversations into a working plan

How did we get here?

- ▶ Mid 1970's (Karen Ann Quinlan 1975, Terri Schiavo 2005)
- ▶ Patient Self-Determination Act 1990
- ▶ Advance Directives
 - Living Will, DPOA for Healthcare (late 1980's)
 - 5 Wishes (2009)
 - Conversation Project (2013)
 - Honoring Choices Idaho (2016)
- ▶ POST/POLST/MOLST (late 1990's)
- ▶ CMS/TJC regulations

Requirements for forms and documentation, but no requirement for conversations.

What are the issues?

- › Cultural misconceptions
- › Improved advanced medical treatments
- › Phenomenal \$\$ associated with these treatments
- › Silver Tsunami—10,000 baby boomers turning 65 every day in the US
- › Baby boomers are control freaks!
- › Quantity does not equal quality

Gap between what patients want and what they get.....why?

- › Conversations don't occur prior to a crisis
- › Start too late
 - Think they don't have to think about it till they're on their deathbed
- › People are too sick
 - Living longer, multiple co-morbidities
 - Usually asked at time of admission when they want help!
 - Patient and Family are stressed
- › People want to "Be a good patient"
- › Depend on their provider to initiate the conversation
- › Wishes are not known and/or clear
- › Orders and legal documents are made without conversations and/or documentation
- › Documents are never completed; can't be found; lawyers office; safety deposit box; family hiding

<https://www.honoringchoicesidaho.org/acp-videos/>

Obstacles to communication:

- › Don't understand the disease
- › Poor understanding of options
- › May be experiencing a decrease in decision making mental capacity d/t age or disease
- › Fear of abandonment
- › May be trust issues
- › Regulations put emphasis on the document, not the conversation
- › Current AD documents are too jargon laden and vague, confusing, and incomplete to adequately capture an individual's wishes.
- › Current documents focus on the needs of medical and legal practitioners to the exclusion of the needs of patients.
- › Conversations can put healthcare workers in an awkward position

Don't want to talk about it

- ▶ 90% people say talking with loved ones about care is important. Only 27% have done so.
- ▶ Patients report unmet need for communication and information from providers about:
 - Extent of disease
 - Prognosis
 - Treatment options
 - Intent of options
 - Adverse effects
- ▶ Healthcare providers don't want to, don't have time, don't want to bring it up, feel uncomfortable

Patients and families should insist.

And more.....

- ▶ There may be mental challenges
- ▶ There may be disagreement. The chosen HCA wishes may be different than the patient's
- ▶ There may be family disagreement
- ▶ The person's doctor may be in disagreement
- ▶ Medical opinions are in conflict

Lack of Training

- ▶ Provider
- ▶ Nursing
- ▶ Support staff
- ▶ Administrators

Engaging patients & families

- Move ACP upstream and the conversation becomes a “normal” part of routine healthcare and wellness
- Patient needs to be involved
- Productive, relevant and emotionally safe
- Sense of control and completion
- Strengthen relationships, not breakdown
- Shared understanding of what matters most
- Symptom management and quality of life
- Too many assumptions



Serious Illness Conversations

- Who is the speaker?
- Who is the audience?
 - Is a support person or HCA present?
- When?
- Where?
- What is being discussed?
- Who's the expert?
- Is pre-work needed?



Communication strategies

- Ask-Tell-Ask
- SPIKES
- NURSE
- GUIDE



Key to effective communication:

- ▶ Set the stage
- ▶ Set up the conversation:
 - Introduce purpose
 - Prepare for future decisions
 - Ask permission
- ▶ Assess understanding, preferences, values, worries, and tolerance for trade-offs.
- ▶ Share the prognosis
 - Allow silence, explore emotion



Explore key topics

- Goals
- Fears and worries
- Past experiences
- Sources of strength
- Critical abilities
- Trade-offs
- Family
- ▶ Close the conversation
 - Summarize
 - Make recommendations, reframe goals
 - Check in with the patient
 - Affirm commitment



When there's no good choices:

- ▶ The patient should guide their life, not the doctor
- ▶ Doing whatever the physician thinks is appropriate, may not be what the patient wants, or what the patient might accept as OK
- ▶ Doing "all that can be done" may not be the most compassionate or right thing to do
- ▶ When presented with the options, what does the patient want?



Questions to ask:

- ▶ What does the patient hope for?
- ▶ Focus on the moment
- ▶ Risks, safety issues?
- ▶ What are the patients biggest fears, worries?
- ▶ What abilities are so critical to life that life can't be imagined living without them?
- ▶ What gives them strength when thinking about health issues?
- ▶ How much is the person willing to go through if their condition worsens?
- ▶ How much does their family know? Understand?

Closure:

- ▶ Clarify and empathize what you heard:
 - "I wish"
 - "I am worried that"
 - "I've heard you say....."
 - "I recommend that we....."
 - "Would you me to talk to your family, friends?"
 - "How does this sound to you?"
 - "I will do everything I can to help you through this"

Make a plan:

- ▶ Document the outcomes of the conversation
- ▶ Clarify any outstanding issues.
- ▶ Prepare and complete legal paperwork with supporting documentation

THE Document

- ▶ Advance Directive, a guide for health care providers that typically includes:
 - Living Will—preferences for future medical treatment
 - Durable Power of Attorney for Healthcare—names HCA
- ▶ POST form
 - For persons with a serious illness and/or limited life-expectancy who wish to specify life-sustaining treatments they do or don't want. Should NOT be used as routine code status order!



Advance Directive facts:

- ▶ HCA only goes into effect if a person is unable to communicate or make decisions for themselves
- ▶ A Living Will goes into effect only if the person is unable to communicate or make decisions for themselves **and** the person is in a terminal, incurable or irreversible state **and** the application of life-sustaining procedures would serve only to prolong artificially a life
- ▶ Death is imminent, whether or not artificial life-sustaining procedures are utilized **or**
- ▶ Person is in a persistent vegetative state



AD process:

- Explore understanding of illness
- Explore experiences (including past hospitalizations)
- Explore living well. Abilities that are most important
- Uncover gaps in information
- Empowers individual with skills to make informed healthcare decisions
- It should not be just about DNR
- Remember—a POST does not name HCA!
- Create a plan that honors individual's preferences, values and decisions



Completing the process

- Distribute information to care teams
 - Communicate with key clinicians
 - Documents to associated healthcare facilities (hospitals—maybe multiple)
 - Secretary of State AD Registry
- Conversations and documents are not a one and done thing.
- Wishes may change as situations change.
- 6 D's



Good Communication Outcomes

- Improved trust of medical community
- Improved patient and family satisfaction
- People will understand their options and get the care they want
- Support resource needs identified earlier
- Documentation and documents will be accessible
- Patient wishes respected
- Families and patients won't suffer
- Less family distress during stressful time
- Less PTSD
- Healthcare staff have improved work gratification



Consequences of not communicating:

- Lawsuits
- Unhappy patients/families
- Bad press
- Not likely to recommend
- Dissatisfied staff
- Poor provider relationships
- Effects on the bottom line



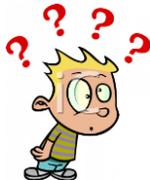
Bottom Line

- ▶ How can we care for people if we don't know what their wishes or preferences are? Where are plans?
- ▶ Advance Care Planning is important for all adults, all ages, no matter their medical status
- ▶ ACP is everyone's responsibility
- Component of routine care
- Normalize the conversation
- Improves communication with families and providers
- Earlier referrals to support resources
- ▶ AD's should be used as a guide for the plan of care
- ▶ POST forms should not be routine but reserved for patients who meet the criteria.

In the end....

- ▶ It's not about the document
- ▶ It's about what the patient wants
- ▶ It's about preserving human dignity
- ▶ It's about having processes in place to support patient choice
- ▶ It's about controlling costs for unwanted care
- ▶ It's about creating plans of care that work, that all care givers are on board with
- ▶ It's about respect for our patients

Questions?



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