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Difficult Conversations: Not Just For Death and Dying

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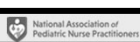


Experts in pediatrics, Advocates for children.

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Speaker Disclosure

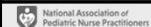
- I have no relevant financial or nonfinancial relationships to disclose.



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Learning Objectives

- Identify commonalities of difficult conversations.
- Manage common barriers to effectively and empathetically engage in difficult conversations.
- Theorize the use of evidence-based approaches to preparing for and engaging in difficult conversations.
- Explore interventions to support the mental health needs of providers who engage in difficult conversations.

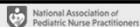


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What are difficult conversations?

- Conversations that:
 - involve serious concerns to the patient or loved ones.
 - are identified by the provider or patient as being confrontational or involve high-stakes subjects such as:
 - New medical diagnosis that may alter patient or family's life
 - Progression of chronic condition
 - Treatment requirements and possible complications
 - Medical error
 - End-of-life

Prober et al., 2022; Yazdanparest et al., 2021



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Why are some conversations difficult?

Patient/Caregiver/Family

- Fear
- Concern of unknown, threat to future plans
- Lack of understanding or misunderstanding
- Social and cultural views
- Family dynamics

Provider

- Feelings of inexperience, awkwardness, or failure
- Fear of causing pain
- Sympathetic pain
- Social and cultural views
- Lack of education, experience

Buckman, 1992; Buckman 2010

Why are some conversations difficult?

- The provider and family historical knowledge and experience affects the conversation.

- Medical
- Personal experiences (positive and negative)
- Beliefs
- Expectations

Guiding principles for the provider

- Avoid being judgmental
- Do not mislead
- Be compassionate and empathetic
- Offer hope
- Remain calm
- Actively listen
- Take occasional pauses
- Allow silence

Limbo & Kobler, 2013; Probes, et al., 2022

Benefits of skillfully having difficult conversations

- Improved psychological adjustment by patient and family
- Facilitates future discussions
- May improve the grieving process
- Decrease rate of burnout in providers
- Decreased stress

Buckman, 2010

Preparing to have the difficult conversation

- Do you or someone on the team have connection to patient or caregivers?
- What information is essential to convey?
- Ensure you have adequate and correct information
- Have answers to anticipated questions
 - Treatment options
 - Plan of care
 - Prognosis
- Be emotionally prepared

Buckman, 1992; Prober, et al., 2022; Rosenzweig, 2012; Whittenber-Lyles, et al., 2013

Preparing to have the difficult conversation

- Will other team members be present?
- Is additional support services and team available to participate?
- Arrange appropriate place for conversation
 - Private
 - Comfortable
 - Minimize distractions
- Allow adequate time
- Reflect on your personal bias, beliefs, and nonverbal communication prior to having the conversation

Buckman, 1992; Prober, et al., 2022; Rosenzweig, 2012; Whittenber-Lyles, et al., 2013

What do they know or need?

- Determine the patient and caregivers':
 - Current medical knowledge and understanding
 - Health literacy
 - Preferred method of information delivery
 - Past or recent health experiences
 - Development level
- Will they need or prefer a support person?
- Does the caregiver(s) prefer to receive information without the patient present?

Buckman, 1992; Prober et al., 2022; Wittenberg-Lyles et al., 2013

Powerful words and phrases

Instead of:

"Everything happens for a reason."

"What doesn't kill you makes you stronger."

"I know how you feel."

"God has a plan" or "God is in control"

Consider this:

"I'm so sorry. You don't deserve this."

"You are strong, but I am here if you need me"

"I am sorry to hear that you are going through this. Would you like to talk about it?"

"You will be in my thoughts and prayers" or "I will be thinking of you"

Having the conversation

- Assess the patient or caregiver's understanding
 - "What is your understanding of Johnny's illness?"
- Give a "warning shot"
 - "The test results were not what we were hoping for"
- Present the information in words the patient or caregiver will understand. Avoid medical jargon or terms
- Allow silence.
 - This happens when the patient or caregiver has intense feelings they need to process
 - If silence must be broken, you may ask "What are you thinking about?"

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Having the conversation (continued)

- Silence is golden
- Do not interrupt
- Encourage questions and answer them directly
- Hear the patient or caregiver
 - Use a few words the patient or caregiver used in their sentence to show that you hear what they are saying (Repetition)
 - Paraphrase what you are told (Reiteration)
 - Reflect on what the patient or caregiver has said (Reflection)
- Ask open-ended questions

Buckman, 1992; Prober et al., 2022; Wittenberg-Lyles et al., 2013

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Having the conversation (continued)

- Watch for nonverbal communication
- Convey hope without providing false assurances
- Repeat important facts
- Use empathy throughout the conversation
 - "It must be difficult to remember all of the information I am giving"
- Provide diagrams and written materials when possible
- Reinforce your ongoing support for the patient and caregivers

Buckman, 1992; Wittenberg-Lyles et al., 2013

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The SPIKES Framework

- Setting
- Perception
- Involvement
- Knowledge
- Emotion, empathy
- Strategy, summary, self-reflection

Wolfe et al., 2014

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SPIKES: Setting

- Select a quiet and private location with enough room for all who will attend.
- Notify all team members who will be present.
- Determine if patient will be present and have appropriate support (Interpreter, Child Life, support person for family)
- Medical team discuss findings and recommendations before the meeting.
 - Determine who will lead discussion
 - What are team goals?
- Limit interruptions (pagers and phones off)

Wolfe et al., 2014

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SPIKES: Perception

- Determine what is the patient and family understanding
 - "What have you been told about your child's medical condition so far?"
- Determine the level of comprehension
- Allow the patient and caregiver to speak without interruption
- How much information is desired at this time?
- Use empathetic communication skills
 - "You must be very worried"

Buckman, 1992; Rosenzweig, 2012; Wolfe et al., 2013

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SPIKES: Involvement

- Explore how much the patient and caregivers want to know
- Do not shatter the patient or caregiver's coping mechanisms.
 - Show respect for the level of information that is desired but ensure that enough knowledge is provided for informed consent if further testing or procedures are needed.
- Encourage questions and answer truthfully
- Reinforce of future opportunities to meet and discuss
- Consider the family's culture, race, religious or spiritual beliefs and socioeconomic background

Buckman, 1992; Rosenzweig, 2012; Wolfe et al., 2013

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SPIKES: Knowledge

- "Fire a Warning Shot" – let them know that the news is not good
 - "I have difficult news to share"; "I am sorry to tell you"
- Pause after this to give time for processing
- Review the information in a few sentences and then PAUSE
- Allow patient and family to ask questions or make comments before moving on
- Present news based on the determined level of understanding
- Avoid medical jargon, euphemisms
- Provide visuals: pictures, diagrams, trends of lab work
- Point out positives when possible
- Choose your words carefully

Buckman, 1992; Rosenzweig, 2012; Wolfe et al., 2013

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SPIKES: Emotion/Empathy

- Anticipate a wide range of emotions
- Engaging in empathetic communication with assist with awkwardness
 - "I can tell this was not the news you had hoped for"
- Validate the patient and caregiver's emotions
 - "I understand how you feel that way"
- Clarify thoughts and concerns by using exploratory questions
 - "Tell me more about how you feel", "What do you mean"
- Actively listen and be fully present, allowing for pause so patient and caregivers can respond

Buckman, 1992; Rosenzweig, 2012; Wolfe et al., 2013

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SPIKES: Strategy, summary, self-reflection

- Are the caregivers or patient ready to discuss the next steps?
- Ensure the patient and caregivers are part of the decision process and actively involved in the discussions
- Verify understanding of the diagnosis, treatment plan or next steps
- Find a balance between hope and realism
- Offer to provide this information with others (siblings, grandparents, other family members)
- Include information on support services
- Reflect on the conversation, pre-planning, outcomes with other team members to determine ways to improve and what was well-done.

Buckman, 1992; Rosenzweig, 2012; Wolfe et al., 2013

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Special pediatric considerations

- Never assume the pediatric patient's level of perception and understanding.
 - Know developmental norms
 - Understand they do not always apply
- Individualize the conversation
- Watch closely for nonverbal communication
- Be honest

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Special pediatric considerations

- Ask open ended questions to understand what they heard and the level of understanding
- Validate the patient's concerns and support their feelings
- Provide resources that are developmentally appropriate
- Consult Child Life for additional support if it is available
- Be mindful of online resources patients and parents may access

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Questions?