Navigating Goals of Care Discussions & Difficult Conversations in Medicine

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Session Objectives

- Define goals of care and explain its significance in complex medical decision making.
- Learn key principles for delivering difficult news
- Practice utilizing a structured framework for sensitive or difficult discussions
- Recognize common barriers and pitfalls that impact communication in healthcare
- Leave with scripts, phrases, and reference tools for real clinical use

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Disclosures

- Author of a book focused on supporting those living with cancer
- Receive small royalty, some of which is donated to the American Cancer Society
- No industry or pharmaceutical relationships to disclose.

Have you…

- Who has led a code status discussion before?
- Who has led a goals of care discussion before?
- Who has left one of these difficult conversations feeling uncomfortable?

Importance of Effective Communication



Prevalence of Communication Failures

- Per the Joint Commission, ~67% of communication errors relate to patient handoff. Most frequent cause of harmful medical errors



Impact on Patients

- 1 in 10 patients are harmed in the healthcare setting. Patient safety incidents result in >3 million annual deaths worldwide

- Poor communication is often a contributor to safety incidents-- poor communication between patient-provider and/or provider-provider.



Malpractice Claims

- In the US, 30% of malpractice claims were due, at least in part, to communication failure

- Resulting in 1,744 deaths and $1.7 billion in malpractice costs over 5 years (published by Harvard Med Risk Mgmt, 2016)



Provider Communication Challenges

- Lot of channels to communicate; ways things can be missed/misinterpreted

- Study: 53% of healthcare professionals report communication disconnects at least *weekly*



Sentinel Events

- Joint Commission reports inadequate communication as the root of over half of serious adverse events in accredited hospitals

Effective communication is *critical!*

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Principles of Effective Communication



Active Listening

- Avoid interrupting. Use non-verbal cues (nod, eye contact). Paraphrase to confirm understanding
- Builds trust with patient + family and improves satisfaction



Empathy and Compassion

- Important that your patient feels understood and respected
- Be conscious of your tone of voice, nonverbal communication
- Acknowledge emotions without judgment; validate difficulty of their situation



Clarity and Transparency

- Use plain English; avoid medical terms
- Be honest about outcomes, while maintaining hope
- Pause to check your patient and/or family understand

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Principles of Effective Communication



Ask open-ended questions

- What do you understand about your diagnosis?
- What matters most to you as you think about the future?
- What are you hoping treatment will achieve?



Use the Ask-Tell-Ask Method

- Ask the patient for their understanding, provide information, ask for their questions/thoughts

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Goals of Care (GOC) Discussion

- **What is a GOC discussion?**
  - A conversation between healthcare provider(s), a patient, and often their family/loved ones, held to gain a better understanding of a patient's values, preferences, and priorities to guide their care plan.
  - Can happen at any stage of illness and is not necessarily limited to advanced or terminal illness
  - About understanding values, aligning treatment w/ values, supporting patients and families through uncertainty
- **Timing:**
  - Anytime, but most often after a significant diagnosis or change in condition
- **What it is NOT:**
  - GOC discussions are not about telling the patient what to do. They are about understanding their values and helping them make informed decisions.

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End of Life (EOL) / Code Status Discussions

- **End of Life:**
  - Similar to GOC but specific to care plans when someone is nearing EOL.
    - *Typically involves decisions about comfort care, hospice settings, or stopping life-prolonging treatments*
  - Narrower focus than a GOC meeting
  - Emphasis on prepping for final stages of life. Includes discussion about symptom management/QOL, what one might expect, emotional/spiritual support resources, legacy planning, child life services if applicable, etc.

- **Code Status:**
  - Often a part of GOC conversations
  - Explore patient's values including acceptable outcomes and tradeoffs
  - Provide patient with understanding of CPR/advanced resuscitation, similar to obtaining informed consent prior to surgery
  - You *can* make a knowledge-based recommendation

Evidence Based Communication Strategies

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SPIKES Protocol

- **SPIKES – A 6-Step Protocol for Delivering Bad News**
  - **S**etting
  - **P**erception
  - **I**nvitation
  - **K**nowledge
  - **E**xplore emotions
  - **S**ummarize

- Developed by three oncologists as a framework for having difficult discussions.
  - A systematic review of 37 studies found that using SPIKES protocol led to significant improvements in learner satisfaction, knowledge acquisition, and performance in delivering bad news.
  - Medical professionals felt more confident in their ability to disclose difficult medical information to their patients, ultimately improving overall communication.

SPIKES Protocol – Delivering Bad News

- **S**etting
  - Appropriate place. Quiet. Include or exclude the patient?
- **P**erception
  - Can you help me understand what you know so far?
- **I**nvitation
  - May I share the results of (your recent scan, labs)?
  - Would it be ok if we talk about what's most important with your care going forward?
- **K**nowledge
  - Use plain language, avoid medical jargon
  - Warning, Pause, Share >> "*I have some serious news to share with you today… …Your cancer is progressing.*"
  - Ask-Tell-Ask >> *Ask what they know, tell what you know, ask what that means to them/questions*
- **E**xplore emotions
  - "I wish I had better news. I can only imagine how upsetting this may be. Help me understand what you're feeling."
  - "I can see this is really overwhelming for you, and that is completely understandable."
  - "What worries you most right now? What's on your mind as we talk about this?"
- **S**ummarize
  - Align treatment options with their values, summarize and check understanding, provide next steps

REMAP – Addressing Goals of Care

- **R**eframe
  - Why the current plan isn't working
  - "Given this news, it seems like a good time to talk about what to do now. We're in a different place."
- **E**xpect
  - Emotion. Respond with empathy
  - "I can see you're overwhelmed/concerned. This is hard."
  - "Is it ok for us to talk about what this means?"
- **M**ap
  - What's important?
  - "Given this information, what is most important for your care moving forward?"
  - "When you think about the future…"
- **A**lign
  - With the patient's values
  - "Listening to what you've said, it sounds like the most important things to you are …. Is that right?"
- **P**lan
  - Match values
  - Discuss next steps. How to best try and match patient's wishes if clinically able.

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NURSE – Respond to Emotion with Empathy

- **NURSE**
  - **N**ame
  - **U**nderstanding
  - **R**espect
  - **S**upport
  - **E**xplore

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EMPATHIC RESPONSES					
Naming	**Understanding**	**Respecting**	**Supporting**	**Exploring**	**"I Wish"**
This must be… • Frustrating • Overwhelming • Scary • Difficult • Challenging • Hard	What you just said really helps me understand the situation better.	I really admire your • Faith • Strength • Commitment to your family • Thoughtfulness • Love for your family	We will do our very best to make sure you have what you need.	Could you say more about what you mean when you say… • I don't want to give up • I'm hoping for a miracle	I wish we had a treatment that would cure you (make your illness go away).
I'm wondering if you are feeling … • Sad • Scared • Frustrated • Overwhelmed • Anxious • Angry	This really helps me better understand what you are thinking.	You (or your dad, mom, child, spouse) are/is such a strong person and have/has been through so much.	Our team is here to help you with this.	Help me understand more about…	I wish I had better news.
It sounds like you may be feeling …	I can see how dealing with this might be … • hard on you • frustrating • challenging • scary	I can really see how (strong, dedicated, loving, caring, etc.) you are.	We will work hard to get you the support that you need.	Tell me more…	I wish you weren't having to go through this.
In this situation, some people might feel …	I can see how important this is to you.	You are such a (strong, caring, dedicated) person.	We are committed to help you in any way we can.	Tell me more about what [a miracle, fighting, not giving up, etc.] might look like for you.	I wish that for you too. [In response to what a patient or family members wishes, such as a miracle]
I can't even imagine how (NAME EMOTION) this must be.	Dealing with this illness has been such a big part of your life and taken so much energy.	I'm really impressed by all that you've done to manage your illness (help your loved one deal with their illness).	We will go be here for you.	Can you say more about that?	I wish we weren't in this spot right now.

Goals of Care Conversations training materials were developed and made available for public use through U.S. Department of Veterans Affairs contracts with VitalTalk [Orders VA777-14-P-0400 and VA777-16-C-0015]. Updated June 2018.

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CPR Statistics

The below stats depict the % of people who **survive** cardiopulmonary resuscitation (CPR) **and discharge** from the hospital after an IN-HOSPITAL cardiac arrest. *These #'s do not specify patient condition at time of discharge including any resuscitation-related adverse event(s) that occurred (ex: vent dependent, stroke, brain death, organ injury/broken bones, altered neurocognitive status, decreased independence, etc.).*

- On TV: majority of people are portrayed to achieve ROSC and discharge
- In-hospital cardiac arrest, general population: 15-25%
  - *Comparison: out-of-hospital cardiac arrest: 10-12%*
- Elderly: 3.8%
- **Cancer: overall ~6.2%**
  - Meta-analysis: 39 years of data analyzing 42 studies and including 1707 adult cancer patients
    - Localized disease: 9.5%
    - Metastatic disease: 5.6%
    - Heme/BMT-CT patients: generally, a lower chance of survival and survival to discharge than solid tumor
    - ICU HemOnc/BMT-CT patients: lower chance of survival compared to gen med/surg units (2.2%)

CPR Statistics Limitations

- While it's a primarily US based meta-analysis, data spans 1966-2005. Multiple hospitals. Some different countries.
  - Survival differs based on comorbidities, not easily controlled for here
  - Possible selection bias: who was offered CPR?
  - Publication bias, etc.
  - Outcomes possibly overestimated- doesn't consider all cancer patients. DNR patients not included hard to say if would've survived attempt.

- **Conclusion**: This data gives a general sense of prognosis, but keep in mind, it reflects a very heterogeneous and somewhat outdated population. While imperfect, the data can still be useful when discussed appropriately.

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Talking about Code Status

Types:

- Full Code
- Do Not Resuscitate / Intubate
- Do Not Resuscitate / Do Not Intubate (DNR/DNI)

- **Starting the Conversation:**
  - “I like to talk with all my patients about what matters most to them if their health situation changes.”
  - “I want to make sure we care for you in a way that matches your goals and values.”
  - “Would it be okay if we talked a little about what kind of medical care you would want if things became more serious?”

- **Understanding of illness:**
  - "What is your understanding about what is going on with your illness right now?"
  - "What have other clinicians told you about your illness and what to expect?"

- **Values:**
  - "Are you religious/spiritual?"
  - "What are you hoping for right now?"
  - "What abilities or activities are *so* important to you that you cannot imagine living without them?"
    - *Common themes: independence, being able to interact with loved ones, living as long as possible, not suffering/being in pain*
  - "What is most important to you if your health worsens?"

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Talking about Code Status

- **Acceptable vs Unacceptable Outcomes**:
  - "What would a good outcome look like for you?"
  - "What outcomes would be unacceptable?"
  - "How would you feel about being dependent on machines to keep you alive, artificial nutrition, and/or needing a long-term care facility?"

- **Experience with Serious Illness:**
  - "Have you ever had a friend or family member go through CPR, require a breathing machine (ventilator), or require ICU care?"
  - "Does that influence how you think about your own care?"

- **Longevity vs Quality of Life:**
  - Inquire your patient's stance: "Some people want every treatment possible to live as long as possible, some prioritize comfort even if time may be shorter. How do you feel about this?"

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Talking about Code Status

- **Transition to CPR/Intubation:**
  - “Sometimes when people become very sick, their heart or breathing stop.”
  - “In that situation, we have interventions like CPR (cardiopulmonary resuscitation) and breathing machines that try to restart the heart or support breathing.” This does not always lead to survival or recovery, and some of my patients would rather we not attempt it, which is why I ask everyone about it."
  - “I want to explain what those treatments involve and then hear your thoughts.”

- **Explain CPR and Intubation realistically, patient should be informed to give consent:**
  - "Doing CPR involves pushing hard on your chest with our hands to try and pump blood through your body, giving you electric shocks to try and get your heart beating properly again, putting a tube into your airway to give you breaths, IV medications, and often connecting you to a breathing machine to breath for you."
  - "In people with serious illness like ___, it often doesn't work as well as people hope. In fact, it often does not work. If we can restart the heart, it can leave people very sick afterwards. Sadly, CPR is not guaranteed to bring you back. In people with the type of cancer you have, generally x% survive and are able to discharge from the hospital."
  - "Some risks of CPR include broken bones, organ damage/punctures, internal bleeding, stroke, decreased function including possible decreased brain function, and decreased independence."
  - The alternative, would be allowing for a natural death and ensuring you are kept comfortable. This is called a DNR/DNI or do not resuscitate/do not intubate.

Talking about Code Status

- **Transition to Code Status Question, Link to their Values:**
  - "I know talking about this is hard, and my hope is not to scare you. CPR and advanced resuscitation are significant and can be quite traumatic. My hope is to make sure you can give informed consent regarding your wishes."
  - After hearing all of that, and talking about what is important to you, how are you thinking about this decision for yourself?
  - Avoid asking, "Do you want everything done?" The word "everything" is easily misinterpreted.
- **Validate if your patient is having difficulty making this decision**
  - "Many patients have a hard time thinking about this, that's completely normal.
  - "Sometimes if helps to think about what outcomes you would find acceptable vs unacceptable."

Recommending DNR

- **When Recommending DNR**
  - “Based on what you’ve told me about wanting comfort and avoiding aggressive treatments, I would recommend that we allow a natural death rather than attempt CPR.”
  - “My concern is that time is shorter than we hope, and that we sadly do not have any more medicines or procedures to help. CPR will likely cause more harm than benefit given the extent of your illness, with a very small chance of bringing you back. I would recommend, when the time comes, that we allow your body a natural death and ensure you're comfortable.”
- **Reassurance Regarding/After DNR**
  - “Choosing not to have CPR doesn’t mean we stop caring for you while you're still with us.”
  - "A DNR order does not prevent you from receiving cancer-directed therapy including chemo/radiation, IV fluids, imaging/scans, labs, antibiotics/other medications, etc., should you continue to want to receive them.
  - "With a DNR order, you are telling us you want us to do everything we can to fight with you, so long as you choose that too, but when the time comes and we cannot keep you alive any longer, you'd like to die peacefully."



Applying these principles to GOC & difficult discussions

Time to Practice Skills:

- **Groups of 3**
  - Person #1 = Learner/Clinician
    - Practice skill
    - OK to pause or retry
  - Person #2 = Patient or Family Member
    - OK to challenge clinician/learner
    - Respond to success
  - Person #3 = Observer
    - Listen, provide feedback after
    - Timekeeper

- Please be respectful, listen and give feedback with empathy
- Try to form groups with people of varying comfortability and experience having serious illness conversations

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Activity #1 – Sharing Serious News

- **Jason is a 54-year-old male, previously healthy with no past medical history. He presented with fatigue, weight loss, and abdominal discomfort for about 2 months. A CT abdomen/pelvis showed a pancreatic mass and small liver lesions. He underwent a liver biopsy. His pathology is back and is positive for metastatic pancreatic adenocarcinoma.**
    - Clinician/Learner Goal:
        - Share this serious news clearly and with empathy with Jason
    - Patient options:
        - Terrified
        - Angry
        - Denial

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Reflection #1

- **Learner/Clinician**: How did you feel giving this news to your patient?

- **Patient/Family Member**: What was it like to be the patient hearing such serious news?

- **Observer**: What went well? What do you hope to replicate?

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Activity #2 – Change in Condition

- **Linda is a 72-year-old female with metastatic small cell lung cancer who was admitted to the hospital 5 days ago. She's septic, likely secondary to a biliary obstruction. She's now in the ICU on 2 vasopressors. She'd been nauseated, vomited, and aspirated. She now has increasing oxygen needs (high-flow nasal cannula and may need intubation). She has progressed through 2 lines of chemotherapy and has no further disease-directed treatment options at present.**
  - Clinician/Learner Goal:
    - Discuss goals of care with the patient, her husband, and son who are bedside.
  - Patient or Family Member options:
    - Angry
    - Denial
    - Flat / Disengaged

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Reflection #2

- **Clinician/Learner**: How did the patient/family member's emotions impact the trajectory of your conversation? What about this scenario was difficult?

- **Patient/Family Member**: What felt most important to you?

- **Observer**: What went well? What do you hope to replicate?

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Activity #3 – Address Code Status

- **Margaret is an 84-year-old female with a hx of advanced dementia, CKD stage 3, and heart failure. She was admitted 7 days ago for failure to thrive and an AKI. She has new oxygen requirements (5L NC) from the IVF's she's received and is now experiencing a heart failure exacerbation. Further, the nephrology team is worried about her worsening renal function. This is her 4th hospitalization in 6 months. She is not interested in eating and keeps getting weaker. She is a full code.**

  - Clinician/Learner Goal:
    - Discuss code status with the patient's daughter, Karen, her only child and activated HCPOA
  - Family Member options:
    - Confused – "She survived this before, why is this any different?"
    - Angry – "So you're just going to let her die?"
    - Kind and open to discussion, lots of questions

Reflection #3

- **Clinician/Learner:** Which emotion/response from the family member was the hardest to navigate? What strategies worked well to help you ultimately communicate effectively / align with the patient's family member?

- **Family Member**: What was most important to you as the patient's daughter?

- **Observer**: What went well? What do you hope to replicate?

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Thank you!

- Thank you for your participation today. Please reach out with any questions you may have!