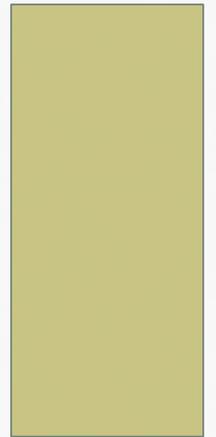


THE FAMILY MEETING



OBJECTIVES

- Review what a family meeting entails, the goals and under what circumstances one should be held.
- Provide an approach to communication between providers and patients.
- Learn how to prepare for a family meeting.
- Understand techniques used in a family meeting.
- Learn how to address emotion and conflict during a family meeting.

What is a family
meeting?

WHY ARE FAMILY MEETINGS IMPORTANT?

- Patients want to be informed.
- Ethical obligation to inform patients.
- Can foster collaboration among family and healthcare providers.
- Improve the patient's ability to plan for the future and set realistic goals.
- Information sharing can be stressful.
- Poor communication can effect clinical outcomes, patient-doctor relationship, patient satisfaction, correlated with higher rates of malpractice claims.

GOALS OF A FAMILY MEETING

- Break bad news
- Assess goals of care
- Communicate medical information (diagnosis, prognosis, etc.)
- Address patient and caregiver concerns or preferences
- Help and guide families with decision-making
- Support family and patient
- Understand your goals are not always the same as the patient's goals

PARTICIPANTS

- Palliative care team (physician, nurse, social worker, chaplain)
- Primary medical team
- Other medical specialist
- Nurse
- Family members, friends
- MPOA/Surrogate
- PATIENT!!!

HOW TO PREPARE

- Know the patient!
- Have a pre-meeting with primary team and/or specialists involved
- Take your time, build rapport

SPIKES MODEL

- S- SETTING
- P- assess patient/family PERCEPTION (ask-tell-ask)
- I- obtain the patient's/family's INVITATION, INVITE them to share information.
- K- Give KNOWLEDGE and information. Assess KNOWLEDGE.
- E- Address EMOTIONS and show EMPATHY
- S- STRATEGIZE and SUMMARY

S-SETTING

- Mental rehearsal
- Review the plan
- Arrange for privacy
- Involve family members
- Sit down
- Arrange seating so you have eye contact
- Have tissues
- Establish rapport
- Manage time appropriately

P- ASSESS PATIENT/FAMILY PERCEPTION (ASK-TELL-ASK)

- Use open-ended questions
 - “What have you been told about your medical situation so far?”
- Correct misinformation, fill in blanks, etc.
- Be sure patient understands

I- OBTAIN THE PATIENT'S/FAMILY'S INVITATION, INVITE THEM TO SHARE INFORMATION

- Some patient's do not want full disclosure.
- “How would you like me to give the information about the test results? Would you like me to give you all the information or sketch out the results and spend more time discussing the plan?”
- If they do not want to know details, offer to speak to a family member/friend.

K-GIVE KNOWLEDGE AND INFORMATION TO THE PATIENT

- Give a warning shot.
 - “Unfortunately, I have some bad news” or “I’m sorry to tell you that...”
- Give information at the patient’s level of comprehension and vocabulary
- Use non-mechanical words
 - “spread” instead of “metastasized” or “sample of tissue” instead of “biopsy”
- Avoid excessive bluntness
 - “You have very bad cancer and you’re going to die.”
- Give information in small chunks and periodically check for understanding.
- Don’t ever say “There is nothing more we can do.”

E- ADDRESS EMOTIONS AND SHOW EMPATHY

- Emotions will vary
- Offer support and show empathy
 - Observe for any emotion
 - Identify the emotion by naming it
 - Use open-ended questions to see what they are thinking or feeling
 - Identify the reason for the emotion
 - Make a connecting statement
 - “I know this isn’t what you wanted to hear. I wish the news were better.”
 - Show empathy- touch shoulder or hand, move chair closer, offer tissue (be sure to assess patient’s comfort level)
 - SILENCE IS OK

E- ADDRESS EMOTIONS AND SHOW EMPATHY

Table 2. Examples of empathic, exploratory, and validating responses

Empathic statements

"I can see how upsetting this is to you."

"I can tell you weren't expecting to hear this."

"I know this is not good news for you."

"I'm sorry to have to tell you this."

"This is very difficult for me also."

"I was also hoping for a better result."

Exploratory questions

"How do you mean?"

"Tell me more about it."

"Could you explain what you mean?"

"You said it frightened you?"

"Could you tell me what you're worried about?"

"Now, you said you were concerned about your children. Tell me more."

Validating responses

"I can understand how you felt that way."

"I guess anyone might have that same reaction."

"You were perfectly correct to think that way."

"Yes, your understanding of the reason for the tests is very good."

"It appears that you've thought things through very well."

"Many other patients have had a similar experience."

HOW TO RESPOND TO EMOTION- NURSE

- N-NAME the emotion
 - “It sounds like this has been frustrating”
 - “I see that this is upsetting”
- U-UNDERSTAND
 - Validates the emotion
 - “It must be so hard to watch your father be kept alive on machines and wonder why this had to happen”
- R-RESPECT
 - “I’m so impressed that you have been here everyday for your father, advocating for him.”
- S-SUPPORT
 - “I will be here to help you as we continue to care for your father.”
- E-EXPLORE
 - “Tell me more about what your father expressed was important to him.”

“I WANT EVERYTHING DONE! I WILL NEVER GIVE UP!”

- Empathetic responses
 - I respect your fighting spirit
 - You have fought long and hard. You are a fighter, that's what you do.
 - I can see how important a cure is to you.
 - Not arguing, being present.
 - I respect your strong faith.
 - I can see how much you love your children and how badly you to to protect them
- Exploratory responses
 - Tell me more about what you mean when by “everything”.
 - What else is important to you if you are not cured?
 - And if long life is not possible?
 - How are your children coping?
 - What gives you strength in all of this?
- Empathy in response to the patient's story
 - I wish things were different.
 - We will support you no matter what.
 - We have counselors who can help you speak to your children.
 - I am inspired by....your courage, the love between you and your family. You have handled your illness as well as anyone I know.
- Reality check
 - I am concerned more chemo will hurt you.
 - Its time to focus on your QOL.
- Aboid at all costs
 - Lets try rehab, if you get stronger we can try.

S- STRATEGIZE AND SUMMARY

- Ask patient if they are ready to discuss a plan.
- Sharing decision-making responsibility with the patient will help physician feel at ease.
- Checking for misunderstanding can prevent false hope, misunderstanding of goals/treatment plan, etc.
- Understanding will lead to better treatment and help frame hope in terms of what is actually possible.
- Patient's who have a clear plan are less likely to feel anxious or confused.

6-STEP FRAMEWORK FROM THE GRS!

1. Prepare for the meeting
 - Have all medical facts available.
 - Prepare an environment.
2. Establish the patient's understanding
 - Explore the patient's understanding of their illness.
3. Determine how much the patient wants to know
 - Not all patient's want to know everything; data suggest this may be true for certain ethnic groups.

6-STEP FRAMEWORK FROM THE GRS!

4. Tell the patient
 - Deliver info in a sensitive, straightforward manner, avoiding technical language or euphemisms. Check for understanding. Phrasing that includes a warning helps prepare patients for bad news.
5. Respond to feelings (NURSE)
6. Plan and follow-up
 - Organize a therapeutic plan that incorporates a follow-up visit and information on how to reach the clinician if additional questions arise.

GIVING HOPE

- Hope for the best, prepare for the worst.
- “I wish....., but I worry.....”
- Introducing new and realistic goals
 - “You’re giving up on him?” “No! We will still treat his symptoms and do everything we can to make him comfortable. To give him the best QUALITY of time to spend with you.

ELICITING VALUES

- Invite the patient into the room
 - “Have you ever talked about him getting worse?”
 - “What is the hardest part of what is going on for you and your family?”
 - “What would he have wanted for himself, knowing how serious his illness is?”
 - “Did she ever talk about his wishes if he had to depend on machines?”

WHEN GIVING PROGNOSTICATION

- Confirm that they would like to hear the information.
- Explore
 - How much do you want to know and who should be present?
 - Is this what you were expecting?
 - Do you want to discuss more?
- “Only God knows what will happen”-
 - It sounds like faith is important to you.
- “Of course it is!”
 - It sounds like you’re not sure if you want to talk about what the future may hold. I know this information can be hard to hear.
- Provide ranges: hours-days, days-weeks, weeks-months, months-years.

MD Anderson- Epner, Crucial Conversations in Patient Care

HOW TO MOVE FORWARD WHEN THERE IS NO CONSENSUS

- Establish a time-limited trial.
- Clearly define the “big picture”.
- Surrogate decision making- “You are not making decisions for him, you are helping us understand what he would want.”
- Follow up.
- Offer support.

ASSESS YOUR OWN EMOTIONS

- Guilt
- Anger
- Fear
- Sadness

COMMUNICATION SKILLS

- Learned
- Do not always improve with time
- Improvement requires active reflection, feedback and practice.
- Interactive workshops more helpful than didactics alone.

COMMON BARRIERS TO EFFECTIVE COMMUNICATION

- Using medical jargon.
- Ignoring the context of the communication encounter.
- Not focusing on patient needs.
- Focusing too much on your agenda.
- Offering reassurance prematurely.
- Fear of giving false hope.

- https://www.youtube.com/watch?v=qHGvjv_7PLU
- <https://www.youtube.com/watch?v=xCBQUGvZU7k>
- https://www.youtube.com/watch?v=jaB9M8B_Tuw

QUESTION 1

- 80 y/o gentleman with newly diagnosed pancreatic cancer. His family, which is of Chinese descent, asks that the oncology team withhold the diagnosis from him. As the PCP, you are asked your opinion on this. Which of the following is the most appropriate next step?
 - a) Tell the patient about the diagnosis.
 - b) Ask the family their reason for withholding the diagnosis.
 - c) Ask the patient about his interest in learning about his medical condition.
 - d) Ask the oncology team to withhold the diagnosis.

QUESTION 1

- 80 y/o gentleman with newly diagnosed pancreatic cancer. His family, which is of Chinese descent, asks that the oncology team withhold the diagnosis from him. As the PCP, you are asked your opinion on this. Which of the following is the most appropriate next step?
 - a) Tell the patient about the diagnosis.
 - b) Ask the family their reason for withholding the diagnosis.
 - c) Ask the patient about his interest in learning about his medical condition.**
 - d) Ask the oncology team to withhold the diagnosis.

QUESTION 2

- 76 y/o F with uterine cancer that is now stable is admitted for vaginal bleeding. She has mild memory deficits but has capacity to make her own medical decisions. She lives in an assisted living facility where she is very happy. During a family meeting, discharge plans are discussed. She is somewhat irritable and desires to go home. Her daughter mentions that she is “afraid of change”. The physicians on the palliative and primary care team think she will get best care in an long-term care facility. The palliative care social worker who has been very involved in the case and has heard her desire to go home, feels that the patient’s wishes should be followed.

QUESTION 2

- What is the best way for the SW to advocate for the patient during the meeting?
 - a) Agree with the physicians decision because it reflects her respect for the physician leader.
 - b) Not say anything at the meeting because it will undermine the team decision but share her thoughts later.
 - c) Say that because the patient has voiced her wish to go home, the team should consider a discharge home with support first.
 - d) Say that long-term care is the wrong decision because she has already discussed the patient's living conditions with her.

QUESTION 2

- What is the best way for the SW to advocate for the patient during the meeting?
 - a) Agree with the physicians decision because it reflects her respect for the physician leader.
 - b) Not say anything at the meeting because it will undermine the team decision but share her thoughts later.
 - c) Say that because the patient has voiced her wish to go home, the team should consider a discharge home with support first.**
 - d) Say that long-term care is the wrong decision because she has already discussed the patient's living conditions with her.

QUESTION 3

- 79 y/o F with pmhx HTN, osteoporosis, rectal cancer 5 years ago s/p surgical treatment, chemo and radiation comes to your office c/o decreased appetite, weight loss, and abdominal distension for the past month.
- PE
 - Scleral icterus
 - Moderate abdominal distension, RUQ TTP, hepatomegaly
- Labs
 - Moderate anemia and liver dysfunction
- Imaging
 - CT chest and abdomen show 2 liver masses suggestive of metastatic disease and ascites
- Biopsy of the liver is positive for adenocarcinoma c/w recurrent, metastatic colorectal cancer with liver involvement.
- Per oncology, she is not a candidate for further treatment and they have recommended hospice.

QUESTION 3

- Which of the following is the most appropriate first step in initiating discussion about hospice?
 - a) Ask the patient to describe her current medical condition.
 - b) Discuss code status.
 - c) Explain hospice and its services.
 - d) Outline prognosis and life expectancy.
 - e) Review the pathology and radiology results.

QUESTION 3

- Which of the following is the most appropriate first step in initiating discussion about hospice?
 - a) Ask the patient to describe her current medical condition.**
 - b) Discuss code status.
 - c) Explain hospice and its services.
 - d) Outline prognosis and life expectancy.
 - e) Review the pathology and radiology results.

CONCLUSIONS

- Family meetings should be part of normal patient care, no matter the situation.
- Prepare accordingly.
- Meetings don't JUST involve palliative care and the patient.
- SPIKES model can be useful in any situation (not just breaking bad news).
- It takes PRACTICE, PRACTICE and more PRACTICE!

REFERENCES

- Baile, WF, Buckman, R, Lenzi, R, Glober, G, Beale, EA, Kudelka, AP, SPIKES- A Six-Step Protocol for Delivering Bad News: Application to the Patient with Cancer, *The Oncologist The official journal of the Society for Translational Oncology*, 2000; 5:302-311.
- Back AL, Arnold R, Tulsky J. Mastering Communication with Seriously Ill Patients. Cambridge University Press. New York, NY: 2009. Smith RC. Patient-Centered Interviewing: An Evidence-Based Method. Lippincott Williams & Wilkins. Philadelphia, Pa: 2002.
- Back AL, Arnold R, Baile W, Tulsky J, Fryer-Edwards KA. Approaching difficult communication tasks in oncology. *CA Cancer J Clin*. 2005; 55:164-177.
- Quill TE, Arnold RM, Platt F. "I wish things were different": Expressing wishes in response to loss, futility, and unrealistic hopes." *Ann Intern Med* 2001;135:551-555
- Durso, SC, Sullivan, GM, eds. *Geriatrics Review Syllabus: A Core Curriculum in Geriatric Medicine*. 8th ed. New York, NY: American Geriatrics Society; 2013.
- MD Anderson Hospice and Palliative Care Board Review 2018- Dr. Daniel E. Epner Challenging Conversations in Palliative Care