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Family Meetings in Hospice and Palliative Care

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Caregivers in Palliative Care

- Family caregivers provide substantial care to patients with serious illness and are themselves in need of care
- Family caregivers are involved in direct care, decision-making, goal setting, and advance care planning
- As professionals, we play a vital role integrating caregivers into the plan of care and supporting them in their roles
- This presentation will cover the family meeting as a best practice for supporting family caregivers in hospice and palliative care including definition, purpose, triggers, challenging clinical scenarios and best practices

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The Family Meeting: Definition

- No single definition exists in the literature
- Valuable clinical tool for:
  - communicating medical information
  - delineating goals of care
  - facilitating decision-making
  - paying attention to patient preferences
  - safe setting in which to process emotions
- Patient should participate if able
- Can be called by patient, family, or staff

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The Family Meeting: Definition

- Interdisciplinary participants
- Usually a physician, a nurse, a social worker, patient, and family
- Intended to address
  - the patient's diagnosis and prognosis
  - the goals of treatment
  - patient and family needs and preferences

Curtis et al, Crit Care Med, 2001

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The Family Meeting: Purpose

- Facilitates communication between team and family
- Strengthens therapeutic alliance between team and family
- Provides a forum to:
  - assess family's strengths and needs
  - discuss the patient's medical condition
  - make joint treatment decisions
  - support the family
  - develop a plan of care

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Family Meeting Triggers: ICU

- Routinely within 72 hours of admission to the ICU
- Mortality risk greater than 25%
- Significant decline in functional status
- Admission to the ICU after 10 or more days in the hospital
- Older than 80 years of age
- Two or more life-threatening comorbidities
- To discuss procedures under consideration: tracheotomy, ventilator, feeding tube
- Introduce hospice

Gay, Pronovost, et al, J Crit Care, 2009

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Family Meeting Triggers: Palliative Care

- Family conflict or crisis
- Longer length of stay
- Absence of designated healthcare agent
- Major care decisions
- Discharge planning
- To share unwelcome prognostic information

Billings, J Pall Med, 2011

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Family Meeting Triggers: Hospice

- Change in medical status
- Transition point in care
- Advance care planning
- Patient/surrogate decision-making
- Conflict resolution
- Ethical dilemma
- Family distress

Back, Arnold, Tulsky. 2009
Hudson, Quinn, O'Hanlon, 2008

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Best Practices: Anatomy of a Family Meeting

- Preparation phase
- The talk
- Follow-up

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Preparation Phase

- Take time to preplan, review medical chart, speak to team
- Get a medical update from current and former providers
- Invite current and former treating team members as appropriate
- Get input from physician, nurse, social worker, chaplain, others

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Preparation Phase (Cont'd)

- Arrange for a quiet space, dedicated uninterrupted time
- Arrange the chairs in a circle
- Make the best use of the environment, available space

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Preparation Phase (Cont'd)

- Important decisions
  - Who leads the family meeting?
  - Who speaks for the family?
  - Whose agenda is followed?
  - Who takes notes?
  - Who summarizes the meeting in the chart?
  - Who will read the notes?
  - Is there a special form?

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Preparation Phase (Cont'd)

- Optimal number: less is better; number of staff should not overwhelm family
- Optimal time: 1 hour prep time, 1 hour meeting, 30-60 minutes follow-up
- Optimal choice of participants:
  - Patient—in most settings
  - Caregivers invited by the patient
  - Involved healthcare professionals

The Talk

- Introduce purpose of meeting
- Introduce participants
- Make the agenda explicit
  - We arranged this meeting to consider discharge planning options. Is this your understanding of the purpose of the meeting?
- Adopt a conversational tone
- Negotiate the agenda with the patient and caregivers
  - How can we be most helpful to you today?

Hannon, O Reilly, Palliat Support Care, 2012

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The Talk

- Provide information
- Check for family's understanding
- Recognize the emotional effect on patients, caregivers
- Provide support and validation for caregivers
- Provide recommendations for beneficial and against futile treatment
- Assess patient and family's decision-making style

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Competencies in Family Meetings

Validate the central role of caregivers

- Create a safe environment for goals-of-care discussions
- Use open-ended questions
- Help caregivers to process emotions
- Provide direct support to caregivers
- Try to achieve consensus

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Competencies in Family Meetings

Include caregivers in advance care planning

- Include caregivers in decisions and next steps
- Make sure caregivers have a clear understanding of each treatment choice
- Help identify a surrogate if patient is unable to communicate
- Identify family composition, resiliency, vulnerability, social support, cultural beliefs, risk factors

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Competencies in Family Meetings

Help the patient establish agency

- Has the patient designated an agent?
- Does the agent know and agree to assume the role?
- Does the agent understand the patient's wishes?
- Is there a signed Health Care Proxy (HCP) form?
- Is the HCP witnessed?
- Is the HCP locatable?
- Is the agent available to make decisions on pt's behalf?

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Competencies in Family Meetings

Help the patient complete advance directives

- Living Will vs. Oral Advance Directives
- Specific scenarios
- Specific interventions
  - Do not resuscitate (DNR) order
  - Do not intubate (DNI) order
  - Artificial nutrition and hydration
  - Mechanical ventilation
  - Use of antibiotics
  - Hospitalization

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Competencies in Family Meetings

Provide caregiver support

- Use active and empathic listening
- Tailor information to patients' and caregivers' level
- Allow caregivers to speak
- Explain the dying process, so caregivers know what to expect and how to prepare
- Share decision-making to reduce caregiver burden and isolation
- Respond to difficult emotions

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Competencies in Family Meetings

What is said	What is heard
Patient is DNR	Represents a consent process, not a person
Persistent vegetative state	Diminishes the humanity of the dying person
Do you want everything done?	You have a choice between nothing and everything
Hang a morphine drip	I must be dying soon
Referral to hospice	Abandonment by team, no hope

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Competencies in Family Meetings

Words to avoid	Words to consider
Should we stop everything?	Nature is taking its course
There is nothing more we can do	There's nothing more we can do for the (tumor), but here's what we can do for the patient and you
The patient failed chemotherapy	We have to weigh the benefit and burden of each treatment option
Do you want us to do everything?	Let's do the things that make sense medically for the patient as a person, and avoid the things that will not help

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Best Practices: Family Meeting Protocols

- *SPIKES* protocol
  - **S**etting up the interview (privacy; participants; sitting; minimize interruptions)
  - **P**erception (assess patient's and family's perception of the situation)
  - **I**nvitation (ask patient about information disclosure preferences)
  - **K**nowledge (share knowledge and information)
  - **E**motions (address with empathy)
  - **S**ummarize or strategize

Baile et al., Oncologist, 2000

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Best Practices: Family Meeting Protocols

- *Oncotalk* training for oncologists, trainees improves responding to emotional concerns, giving bad news, family meetings, transitioning from curative to palliative care, responding to requests for futile treatments (Back, 2003)

- *Geritalk* improves preparedness of geriatric and palliative care fellows for challenging communication tasks and more deliberate practice (Kelley, 2012)

- *EPEC and ELNEC* have training modules for communication and advance care planning

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Best Practices

- COMFORT Curriculum for Palliative Care Teams
- NCI-funded program, City of Hope
- Training components
  - Two-day training program
  - Development of two new communication skills
  - New patient-centered, narrative, mindful presence approach
  - iPhone app with quick reference guide and toolkit
  - Oxford Textbook of Palliative Care Communication

Wittenberg-Lyles et al., 2014

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Follow-Up

- Offer support services (social work, patient advocacy, chaplaincy, ethics consultation, palliative care)
- Summarize meeting content and action plan at the end
- Ensure a follow-up plan
- Check in with patient and caregivers again
  - Is this what you wanted from the meeting?
  - What haven't we touched on that's important to you?

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Follow-Up

- Document who participated, content discussed, decisions made, outstanding issues, and action plan
- Make documentation available (transparency)
- Check-in with patient, family regarding ongoing concerns
- Provide additional information, as needed
- Debrief with staff

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Challenging Scenarios

- Mrs. R is hospitalized for bowel obstruction secondary to recurrence of GI cancer. She is found to have progressing tumor with associated pain, poor performance, immobility, dehydration, decreased bowel motility, opioid-induced nausea, constipation
- She received chemotherapy and radiation therapy earlier, but disease progression followed soon after. She is being treated with opioids, artificial nutrition, and hydration
- She has been deemed a poor surgical risk due to widespread intra-abdominal disease and multiple points of obstruction

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Challenging Scenarios

- The oncology team asks the palliative care team for help with symptom management and next steps. The palliative care team convenes a family meeting. Participants include: the palliative care fellow, the social worker, Mrs. R's daughter, son-in-law, grandson, and granddaughter

- Mrs. R is somnolent and unresponsive for large periods of time during the day, so is deemed unable to participate

- The fellow begins with an overview of Mrs. R's disease progression, noting symptoms that suggest she has entered the terminal phase. He offers potential medication management to ease her symptoms including morphine, dexamethasone, haloperidol, and octreotide

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Challenging Scenarios

- Mrs. R's daughter is the designated healthcare agent. She reports that her mother would not want to live like this, and that it is her mother's expressed wish to die at home
- The family reminisces about Mrs. R's life, and the social worker lists the options for hospice, home care, or placement in a facility
- As the meeting is wrapping up, the Chairman of Medicine arrives unexpectedly, pulls up a chair and suggests surgery as an option. He is encouraging about surgical resection as a good alternative, and he urges the family to consider more aggressive intervention
- The palliative care team is surprised; the family is confused. The meeting ends without a clear way forward

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Challenging Scenarios

- This case illustrates typical family meeting pitfalls
  - Unclear goals of care
  - Giving pathophysiology lectures
  - Giving family unrealistic hope
  - Disagreements among professional staff
  - Power struggles among staff – chairman versus fellow
  - Unclear meeting agenda
  - Dominance of medical content, little psychosocial focus
  - Challenging role for palliative care consultants

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Challenging Scenarios

- Mr. C is a 48-year-old, first-generation Chinese immigrant rushed to the hospital after complaining of chest pain and collapsing in the bathroom at work
- He is sent to a busy ER in a major medical center
- Mr. C is accompanied by his wife, and joined by his children
- Mr. and Mrs. C speak almost no English; they rely on their children to explain the medical information
- Of the three, the 15-year-old daughter is the most fluent in English

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Challenging Scenarios

- After a cardiac workup, Mr. C is diagnosed with end-stage CHF with a prognosis of weeks to months
- A family meeting is hastily arranged to share the diagnosis and prognosis with the patient and family
- The cardiologist, the ER nurse, physician's assistant, and the family stand around Mr. C's bed in an open cubicle
- Because it is now 10:00 pm on a Friday night, the hospital interpreter has already left for the day
- The ER is crowded and noisy, so the staff decides against use of the language line

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Challenging Scenarios

- The cardiologist leads the discussion and asks the 15-year-old to explain the information to her parents

- She asks the daughter to tell her father that he has extensive heart disease and will have to alter his diet, work, and lifestyle. She reviews the range of treatment options including medication and open-heart surgery. Before leaving, the cardiologist tells the daughter that time is short, and her father should get his affairs in order

- The daughter nods and translates for her parents and siblings. The staff notes her calm and mature demeanor

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Challenging Scenarios

- This case illustrates common cultural challenges
  - Working with caregivers of various acculturation levels
  - Using an untrained family member as an interpreter
  - Ignoring cultural norms: daughter as spokesperson
  - Disregarding cultural taboos: truth-telling as bad luck
  - Ignoring patient's preference for information disclosure
  - Holding a family meeting without patient's consent
  - Excluding nonmedical disciplines

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Best Practices

- Use of a professional interpreter is always preferable
  - Family members may omit information to protect the family
  - Use of children as interpreters can cause emotional strain and is illegal in several states
- Because professional translation is not 100% accurate, say:
  - Please translate everything that is said, word for word
  - I will be explaining technical terms like ‘hospice,’ but let me know about any cultural concerns I should be aware of before we start

Smith, Sudore, Perez-Stable. JAMA, 2009

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Best Practices

- Address concerns proactively
  - Confidentiality: Interpreters are trained to protect patient privacy
  - Immigration: We will not report on your status to immigration
  - Language: “The cancer has spread” not “metastatic disease”
- Make eye contact and speak directly to the family, rather than through the interpreter
- Debrief with the interpreter after the meeting

Smith, Sudore, Perez-Stable. JAMA, 2009

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Family Meeting: Unanswered Questions

- Is the family meeting associated with higher satisfaction?
- What outcomes should be measured?
- Does the family meeting cost or save money?
- Do setting, length, number of participants matter?
- Does individualized planning reduce ad hoc and informal meetings, and save teams time?
- Does the family meeting improve bereavement?
- Can the meeting make things worse?

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Do Family Meetings Help Caregivers?

- The literature on the family meeting is still relatively new
- Existing studies suggest that benefits outweigh risks
- Promising signs
  - Family meetings are associated with less time in ICU, earlier withdrawal of technology, timely referral to palliative care, hospice
  - Model programs show the feasibility of training, upstreaming referrals from ER, changing practice patterns
  - Tools (self-report instruments, family inventory of needs, coaching) can increase caregiver confidence and decrease concerns

Glajchen, Lawson, Todd, JPSM, 2011
Hudson, Thomas, Palliat Med, 2009
Curtis, Crit Care Med, 2001

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Conclusions

- To ensure that caregivers' needs are met, high standards are needed in knowledge, clinical competency, and understanding of best practices in family meetings
- Working with caregivers falls to no one member of the healthcare team, but rather, falls to every member
- The family meeting should be a quality indicator in palliative care and hospice

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