FINDING CALM IN THE STORM: A PALLIATIVE CARE APPROACH TO NAVIGATING THE FAMILY MEETING

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What we will cover today:

- Baggage and preconceptions
- Where do we stand
- The science and art
- Pitfalls and special situations
- Summary
Baggage and Preconceptions

- What do we bring to the meeting?

- What do they bring to the meeting?
How do we define family?
How do they define family?
Suffering

- Your perception of their and their loved one’s suffering
- Their experience of that suffering
Chaos

- Our need to organize and rationalize it into one or a few of our models

- Their need to simplify it and make sense of it in their terms
Fatigue and Exhaustion

- Ours at the end of a 10 to 12 hour day

- Their 24 X 7 experience of the illness
Circling the Wagons

- The “legends” and stories about the family, passed in whispers, winks and nods

- Past challenges: abuse, divorce, wars, immigration, disasters, etc…
What do we know?

Most of our evidence comes out of the ICU where decisions are loaded and emotions, highest.
## Medicare End of Life Trends

Less hospital deaths and more hospice BUT more ICU, more transitions and short length of stay in hospice

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<thead>
<tr>
<th></th>
<th>2000</th>
<th>2005</th>
<th>2009</th>
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<tbody>
<tr>
<td>Deaths in acute care hospitals</td>
<td>33%</td>
<td>27%</td>
<td>25%</td>
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<tr>
<td>ICU use in last month of life</td>
<td>24%</td>
<td>26%</td>
<td>29%</td>
</tr>
<tr>
<td>Hospice use at time of death</td>
<td>22%</td>
<td>32%</td>
<td>42%</td>
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<tr>
<td>Transitions in last 90 days</td>
<td>2.1</td>
<td>2.8</td>
<td>3.1</td>
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<tr>
<td>Transitions in last 3 days</td>
<td>10%</td>
<td>12%</td>
<td>14%</td>
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Most Families are Poorly Prepared

- 70 to 95% of EOL decisions must be made by family members; half the time they do not know anything of the patient’s preferences
- Physicians and nurses poorly anticipate family needs for communication and support
- Family and clinicians often collude to avoid the “elephant in the room”
- Family perception of unpreparedness for patient’s death correlates with greater burdens of grief

Schaefer KG, Block SD. Curr Opin Crit Care. 2009;15:569-77
FIGURE 1. TEMPORAL MODEL OF FAMILY DECISION-MAKING

- **Illness Experience**
- **Family Meeting**
- **Dying Process**
- **Emotional Burden**

**Time**

**Domains Preceding Family Meeting**
- Illness perspective
- Information
- Critical Incidents
- Patient/family communications

**Domains During Family Meeting**
- Preparation
- Support
- Consensus

**Domains Following Family Meeting**
- Supportive gestures
- Information
- Consistency of care and decisions

**Emotional Burden**
- Lingering questions
- Resentments
- Guilt
### EXAMPLES OF FAMILY MEMBER COMMENTS BY STAGE AND THEME

* (+) denotes positive experience and (−) denotes negative experience.

<table>
<thead>
<tr>
<th>Illness experience:</th>
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| Understanding of the medical condition | ▪ “In ICU we were told right away that she had a devastating stroke.” ( + )  
▪ "He just got sick and wasn't feeling good and drove himself to the hospital…I thought he was going to pull out of it…they didn't know what was wrong with him." ( − ) |
| Critical incident occurred | ▪ “…didn’t think to do a CT….until it was almost insisted upon. I am still angry about this.” ( − ) |

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<tr>
<th>Family Meeting:</th>
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| Preparation | ▪ “We all kind of understood that he wasn’t going to get better and it was about that time that we had the family meeting.” ( + )  
▪ "We thought they were going to tell us how to take care of her when she left the hospital”. ( − ) |
| Support for decision making | ▪ “They were giving us information without our having to come up with the questions. When you have not gone through this before, you don’t even know what to ask.” ( + )  
▪ “Not giving us enough time.” ( − ) |

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<tr>
<th>Dying Process:</th>
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| Information about the dying process | ▪ “.. helpful to understand what was going to happen…things you are going to hear and see.” ( + )  
▪ “They never took vitals. She would touch his foot. I would ask her ‘What are you checking for?’ They need to explain a little better.” ( − ) |
| Consistency between decisions and care | ▪ “Even though she could not talk they would look for signs if she was in pain or something.” ( + )  
▪ "There was a wait on a room on a palliative care floor and my dad got put on a regular floor…His instructions were very specific, no food, no water just pain control….What he got instead was oxygen, and being hydrated and being pricked to check his blood sugar levels. And we had to literally argue with the nurse that this is not what the doctors ordered, and this is not what was supposed to happen.” ( − ) |
Summary of Findings- Family Interviews

- For families unsatisfied with EOL care, there is:
  - Poor communication re: prognosis
  - Frustration/guilt over pain management
  - Uncoordinated care (i.e. siloed care)

- **Siloed Care** = Lack of coordination of patient care across people, functions, activities and sites (Shortell 2000)

- **Siloed care fundamentally shapes:**
  - what dying patients (and their families) understand,
  - how patients and families make decisions and
  - How families grieve

Stacey C; Pai M, Radwany S. American Academy of Hospice and Palliative Medicine Annual Meeting 2015
“Having mostly a medical nursing background, working in the trenches... I have seen suffering at the end of life. This is in part due to the attending physician not understanding [end of life care], or the families of these patients not being given the information to make such heart wrenching and difficult decisions.” - RN
Evidence:

- In one study, nearly half the nurses studied left their units or nursing altogether because of moral distress.
- Among 760 nurses, nearly 50% had acted against their consciences in providing care to terminally ill patients.
- Nurses lose capacity for caring, avoid patient contact, and fail to give good physical care d/t moral distress.
- Nurses experience physical and psychological problems as a result of moral distress.
- Nurses physically withdraw from the bedside, barely meeting the patient's basic physical needs, or they leave the profession altogether.
Barriers to Communication

- **Patient/Family factors:** anxiety, denial, mutual desire to “protect” one another.
- **Clinician factors:** lack of training, comfort, and time, difficulties in prognostication.
- **System factors:** life-sustaining care is the default, no systems for end-of-life care, poor systems for recording patient wishes, ambiguity about who is responsible.

Bernacki RE and Block SD. JAMA Intern Med. 2014
More Barriers: Families Love Optimism (but Who Wouldn’t?)

- 546 surrogates of 275 patients in five academic US medical centers
- Surrogates rated quality of prognostic communication
- Surrogates and physicians rated probability of survival on day 3
- Concordance of estimates = < 20% difference
- Concordance achieved only 37% of the time
- Ratings of physician communication by surrogate highest in the overly optimistic 50% of surrogates

And Then There's This…

No matter what.

Fight On.
AND THIS...
Effective Family Meetings Help

Proactive structured family meetings often involving palliative care have improved a broad range of outcomes in over a dozen trials:

- Better family understanding and acceptance
- Decreased PTSD and complicated grief in survivors
- Decreased anxiety and depression in family members
- Better nurse assessed quality of death
- Shortened LOS and lowered costs

Schaefer KG, Block SD. Curr Opin Crit Care. 2009;15:569-77
THE FAMILY MEETING:

A LEARNED AND REPRODUCIBLE SKILL
Prepare: Whom to invite?

Attendees for the family meeting should be approved by the patient, guardian or DPOA if possible and could include:

- Patient (if capable to participating);
- Guardian/DPOA/Spouse
- Family members and other loved ones
- Provider team: RN, SW, chaplain, physicians...
- **Speakerphone** can save time and frustration later
Prepare: Location

- Ample room for all to sit comfortably
- Minimal distractions and adequate ventilation
- Sit close to the door or egress
- Position yourself next to hard of hearing family members
- Accommodate elderly or frail; they may quietly be the most important participants
- Silence or turn off cell phones and/or pagers or leave with someone else
Prepare: Have a plan

- **KNOW THE MEDICAL SITUATION INSIDE OUT, BACK AND FORTH**

- All difficult situations require pre-meeting or huddle and later debriefing with the important providers to assure common understanding and goals as well as residual tasks

- **Try to always include the primary nurse**
  - Establish and agree upon those goals while being flexible towards family needs
  - Have someone sit next to you who can kick you in the ankle when you’re acting stupid
Prepare: Potential Goals

- Assess understanding, concerns, coping
- Share information and provide education
- Provide emotional support for family
- Build trust
- Elicit patient’s goals and values and use these to establish goals of care
- Support and educate team members

Adapted from Billings JA. J Palliat Med. 2011;14:1042-1050
Start well:

Introductions:
- Assure that they understand roles of providers in the room
- And that you understand theirs

☐ SIT DOWN

☐ DO NOT check your watch, phone or pager. do not look at the clock.

☐ Family members read every glance
Schmoozing is a necessity

Ex: “Tell me about (use formal name). Where did he grow up? What did he do?

Try to honor the patient honestly

Capitalize on any trigger at hand: a ring or watch, a picture, the blanket, etc.

Take the patient from two dimensions to three

Allow yourself to be enriched while gaining trust and perspective

What do they know?

- A very common stumbling point is to assume you know what they understand and where they stand
  - “Please tell me about what has happened up to now.”
  - “What have the doctors told you?”
  - “What do you think about all of this?”
Acknowledgement

• Acknowledge the difficulty, pain, and suffering of the patient and family
• Assume they have good reason to feel angry, betrayed, frustrated.
• Take time to positively acknowledge the care they’ve provided if you can be honest
• Let them tell their story but do not allow an outlier to dominate the conversation
Acknowledgement

- “You have been through a lot”
- “I can’t imagine dealing with everything you and your family have faced”
- “I’m sorry about what’s happened. I’ll look into it. We need to do a better.”
- “You have been a great advocate for___”
- “You have done an amazing job caring for____. How can I best help you now?”
Prognosis

- Assess their desire and readiness to hear prognostic information:
  - Have they had time to prepare?

- Assess your own readiness and concerns: How will it affect your communication:
  - What is your level of certainty?
  - How recently have you been greatly humbled by a prediction?
  - What is your anxiety level?
Essential to communicate this clearly but empathically

Avoid euphemisms and jargon

Use ranges: likely scenario, best case, worst case, then return to most likely scenario

Discuss both expected survival, functional status and how the expected future will appear to them

Accept and acknowledge their skepticism of our ability to predict outcomes
Empathy and Support

- Allow silence for family to express feeling.
- Name the feeling.
- Provide non-verbal support.
- Offer tissues, or put a hand on a shoulder.
- Ask them to describe what the tears are about: “Help me understand what is making you so sad/upset/scared.”
- Explore feelings: “Tell me more.”
- Express empathy: “I am sorry that this is so sad/upsetting/scary for all of you.”

Adapted from: Serious Illness Conversation Guide. Ariadne Labs. 2015.
Using “I Wish” Statements

- “I wish I had better news to give you.”
- “I wish things had turned out differently.”
- “I wish it were possible for us to fix this. We would all be a lot happier if that were so.”
- “I wish we had an effective treatment for this.”
- “I wish I could promise you that. It must be very hard to even think about not being here for __________.”

Establish Goals of Care
(Traditional and PC not mutually exclusive!)

Always place in the context of the patient’s values and goals

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<thead>
<tr>
<th>TRADITIONAL</th>
<th>PALLIATIVE</th>
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<tbody>
<tr>
<td>Cure Disease</td>
<td>Relieve Suffering</td>
</tr>
<tr>
<td>Prolong Life</td>
<td>Improve or Preserve Quality of Life</td>
</tr>
<tr>
<td>Improve Function</td>
<td>Stay in Control</td>
</tr>
<tr>
<td>Avoid Premature Death</td>
<td>A Good Death</td>
</tr>
<tr>
<td>Restore Professional and Family Role</td>
<td>Support Family</td>
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Assess Their Understanding

- “Are there others you’ll be speaking with about this? What will you tell them?”
- “We’ve covered a lot of ground today. I need to be sure I am speaking clearly. What for you were the most important things you’ve heard today?”
Plan and Follow Up

- Concisely summarize most important information
- Review overall plan
- Outline next steps
- Agree upon a follow up meeting or touch base, especially if a therapeutic trial is being undertaken
- Introduce other sources of support
- Something in writing?
Pitfalls and Pratfalls
Pitfalls: Missed Opportunities

On analysis of meeting transcripts and videotapes, physicians miss opportunities in several ways:

- Spending more time talking than patient or family
- Not tolerating silence
- Passing over emotions
- Missing teaching opportunities

My Observed and Personal 2 Biggest Sins:

#1 JARGON
“Woah! Slow down, Mrs Marney. Please keep in mind I have to translate all your laymen’s terms into medical gobbledygook.”
#2: TMI
Language with Unintended Consequences

- “Do you want us to do everything possible?”
- “Will you agree to withdraw care?”
- “It’s time we talk about pulling back”
- “I think we should stop aggressive therapy”
- “I’m going to make it so he won’t suffer”
Manage Your Own Expectations

First meeting may be needed just to establish trust and trade info (circle and sniff)

Families may need time and guidance to accept the rapidly changing circumstances thrust upon them

Don’t allow haste to build mistrust; do not sacrifice the good for the perfect

We cannot place their needs secondary to our agenda and jump directly to decisions

“*If it’s so darn hopeless then why do they keep asking me about DNR orders all the time?*”
Getting from here...
To here...

...can be a BIG win!
The “Starving” and “Killing” Questions?

“Aren’t we starving him?”
- “Part of dying naturally is that people stop eating and drinking. This protects them from secretions, etc…”
- “Good mouth care prevents any sensation of thirst or hunger in people who are dying…”

“Is the pain medicine killing him?”
- “I wish it were different, but the cancer and lung disease and heart disease are killing her.”
- “Using the right amount of pain medicine will actually help her live longer though she may sleep a bit more.”
Conflict: a Stepwise Approach

1. Notice the conflict
2. Prepare yourself and monitor your own emotions
3. Nonjudgmental starting point: tactics vs. people.
4. They may have good reason to be angry.
5. Reframe charged issues; restate intentions
6. Respond empathetically
7. Try to meet the needs of both parties
8. If no agreement reached, get help!

Cross Cultural Issues

- Differences in beliefs and preferences regarding:
  - Patient autonomy
  - Disclosure of diagnosis and prognosis
  - Respect for authority
  - Filial piety, spirituality, trust
  - Locus of control/family role

- Best to directly query with an open and respectful curiosity: permission to inform, how decisions are made, sources of spiritual support…

Using an Interpreter

- Always use a professional except for mundane issues.
- Trained medical interpreter is best.
- Brief the interpreter
- Prepare family; assure confidentiality
- Always address patient/family directly
- Use simple short sentences
- Empathic statements should not be forgotten
- Debrief the interpreter

Remember!

- Have a **plan**, confirm with team
- Determine **Who, Where, When**
- **Start well**: what do they know + want to know
- **Speak less** than the family; use silence
- **Clear concise** information + prognosis; no jargon!
- **Acknowledge** emotions; **Assess** understanding
- **Don’t force** decisions prematurely
- **Provide support** and ease guilt
- **Summarize** and **follow up**
THE ULTIMATE GOAL:
GOOD DECISIONS