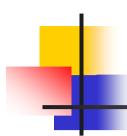
Family Meetings in Intensive Care Units During Crisis: A Qualitative Study

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Introduction

- Over 70% of Intensive Care Unit (ICU) deaths in the USA occur after decisions to withhold or withdraw life sustaining medical therapy (LSMT) or forego attempts at resuscitation
- Only about 5% of these patients are able to participate in such decisions
- Therefore much of the burden of this decisional process is borne by families and loved ones (referred to here as families collectively)



Introduction

- Decisions to limit treatment are reached after family meetings held formally or informally
- Family meetings intend to:
 - Educate and inform family
 - 2. Provide emotional and spiritual support
 - 3. Answer questions
 - 4. Reach consensus on planning care



Summa Health System's Palliative Care Consult Service (PCCS)

- This PCCS began in December 2002 at a 645 bed tertiary care teaching hospital
- Of the 1700 consultations performed between December 2002 and April 2006 700 came from one of Summa's five ICU's
- In-hospital mortality was 41% for PCCS patients and an additional 26% became hospice referrals

Summa Health System's Palliative Care Consult Service (PCCS)

- Reasons for consultation often include end of life issues, decision making, family support and establishing goals of care
- These particular consultations usually lead to family meetings
- All PCCS family meetings were attended by the service's nurse practitioner and/or physician
- Additional involvement came as needed from intensive care physicians and nurses, other consultants, social worker and chaplain



Research Objectives

- Describe factors in family meetings which lead to successful decision making and reduce the emotional burden placed on families
 - We define "successful decision making" as achieving consensus among physicians, family and staff regarding the plan of care for the patient

Methods

- Design: Qualitative study using semistructured, in-depth individual interviews and focus groups.
- Sample: All families who had a loved one die during or after a stay in the ICU and who participated in a decision-making family meeting with the PCCS are being contacted for interviews. About 20% of this sample have been willing to participate.



- 1. Can you describe the family meeting?
- 2. What helped you to come to agreement with providers' recommendations?
- 3. Are there things that comforted you?
- 4. Anything that continues to bother you today?
- 5. How could your experience have been better to ease your emotional pain?

(Questions added until theoretical saturation is achieved)



- Interviews taped and transcribed
- Content is analyzed using methods from grounded theory:
- Interdisciplinary research team to prevent disciplinary bias
- Independent review of transcripts by investigators
- 3. Start with a preliminary framework for domains
- Code comments under the domains (Open Coding)
- 5. Identify major themes in each domain (Selective Coding)



Analysis

- Content is analyzed using methods from grounded theory (cont):
- 6. Identify connections between domains (Axial Coding)
- On-going analysis during the process of data collection
- 8. Work as a group to arrive at consensus (Investigator triangulation)
- 9. Validate findings through participants' feedback
- 10. Build a theoretical model



Preliminary Findings Based on:

- Results from:
 - 10 interviews with
 - 19 family members regarding
 - 13 patients

 Independent review and consensus among three investigators



- Discuss what to expect
- Make decisions about:
 - Possible treatments or surgeries
 - Relieving pain
 - Remove life support
- Give authority to doctors
- Get family together
- Reassure family about what is happening
- Announce a possible recovery

Insight:

 Families did not perceive that the family meeting was to also provide emotional and spiritual support



- Doctors kept me informedcalled telling us what has been done...this is what we can do...
- Knowing options...
- Assured me: "doing all that is possible, but better to let her go"
- Having time needed to decide
- Knowing wishes through a living will
- Consensus among the doctors

Insight:

- Decision making process enhanced by-
 - Information
 - Sound logic
 - Consequences of choices
 - Time to think



- Nothing was hidden
- People listened
- Reassured she was not suffering
- Informed me about what to expect during the dying process
- Staff assured me she would want this
- Dr said: "she is giving up, it is time to let her go."
- The nurses let us stay in the conference room to be close
- Nurses kept us informed about keeping him comfortable

Insight:

- A comforting process was described as -
 - Building trust
 - Compassionate gestures
 - Speaking for the patient to ease family guilt



- Not aggressive
- Self assured
- Keeps you calm enough to keep your mind working
- Honest
- Gentle
- Professional
- Calm
- Patient
- Compassionate

Insight:

 These traits may influence consensus building and reduce emotional burden later

Lingering Issues for Families: Connections between Domains

When decisions are made without families receiving adequated information, questions linger ---

- Was there a mistake made to lead to this?
- Could something have been done sooner to prevent the death?
- Were there options not pursued which could have saved him?

When staff lack comforting skills, families report ---

- Feelings of guilt or doubt about decisions
- Feelings of abandonment after withdrawing life support



- Debriefing meeting after withdrawing life support or after the death
- Adequate <u>space</u> for families to stay nearby
- Earlier <u>information</u> about and use of family meetings
- Don't rush the decision making process



Study Limitations

- Families were unable to accurately identify PCCS meetings retrospectively
- How were the 20% who agreed to participate different from those who declined?
- Dependence on family recall and variable time between hospitalization and focus group/interviews



Ethical Issues

- Do these discussions open old wounds? How do we best support families through this?
- Should bereavement referrals be made, and if so, to whom?
- What if specific residual medical questions are uncovered during the interview? Should the researchers seek answers for families?



Future Directions for this Study

- Comparison of bedside nurse, attending physician and family perspectives on the same patients. Incorporate FAMCARE data into this analysis.
- Follow up with families a second time to:
 - Assess conclusions' validity and reliability
 - Evaluate the effect of the focus group process; was the research therapeutic, harmful, neutral?
- Develop protocol for residual medical questions

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- Curtis JR and Rubenfeld GD, eds. <u>Managing Death in the ICU</u>. Oxford University Press 2001.
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