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:
  1. 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 semi-structured, 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.

General Exploratory Questions Based on Preliminary Concepts

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)

Analysis

- Interviews taped and transcribed
- Content is analyzed using methods from grounded theory:

1. Interdisciplinary research team to prevent disciplinary bias
2. Independent review of transcripts by investigators
3. Start with a preliminary framework for domains
4. 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)*
7. 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

Purpose of Family Meetings

Families said:

- 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

What helped you come to consensus?

Families said:

- Doctors kept me informed-called 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

What helped to ease emotional pain?

Families said:

- 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

What health care provider traits are important?

Families said:

- 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

Family Recommendations to Improve Services

- **Debriefing** meeting after withdrawing life support or after the death
- Adequate **space** for families to stay nearby
- Earlier **information** 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. Managing Death in the ICU. Oxford University Press 2001.
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