

Comparing Families' and Nurses' Experiences:

A Content Analysis of Comments on ICU End-of-Life Care

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Acknowledgements

- Mentor: Sarah Shannon, PhD, RN
- Rheba de Tornyay & the deTornyay Center for Healthy Aging
- Integrating Palliative and Critical Care (IPACC) study team
- Randy Curtis, PI of IPACC study
- Honors seminar leader: Karen Thomas



Problem

- Approximately 20% of all Americans die in an intensive care setting¹.
- Studies are showing a continued increase in intensive care use as well as increased numbers of ICU beds².

1. Angus, D.C. Use of intensive care at the end of life in the United States: An epidemiologic study. *Crit Care Med* 2004;32(3):638-643.
 2. Sharma, G. trends in end-of-life ICU use among older adults with advanced lung cancer. *Chest* 2008; 133;72-78.
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Problem

- While ICU EOL care is pervasive, limitations in clinicians' EOL care skills are common^{3,4}.
- ↳ Studies identify key domains of EOL care:
 - Pain- and symptom control
 - Communication
 - Whole person domains (e.g., preparation for death)
 - Conflict resolution (e.g., on life support)
 - Interdisciplinary team approach
 - Trust

3. Faber-Langedoen K. Dying patients in the intensive care unit: Forgoing treatment, maintaining care. *Academia and Clinic* 2000 8?-?

4. Mularski, R.A. Quality of dying in the ICU: Ratings by family members. *Chest* 2005 128:280-287

IPACC Study

- The Integrating Palliative and Critical Care study (IPACC) was conducted at 15 hospitals in the Pacific Northwest.
- A survey assessing the quality of the ICU experience and care provided was sent to 2817 nurses and 2461 family members between (8/14/03 and 12/13/07) following the death or transfer of a patient who had received ICU care.
- Of the 1029 surveys from nurses and 855 surveys from family members that were returned, a total of 695 included comments: 169 from nurses and 526 from family members.

Purpose of this sub-analysis

- To explore participants' responses to two open-ended questions in the IPACC survey on "*what was done well*" and "*what could have been done better*" in the care of your loved/this patient.
 - To describe the key themes for family members and nurses around care of patients dying in the ICU setting.
 - To compare family members' and nurses' perceptions of EOL care in the ICU.
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Methods

- Content analysis: subjective interpretation of text data through coding and identifying themes.
 - All data were coded by investigator (student) and reviewed by mentor.
 - Comparison of rank ordering of themes between two groups of respondents: nurses and family members.
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Findings

	Family		Nurse		Total
	Negative	Positive	Negative	Positive	
Quality of Care Domain					
Quality of Care (general)	59	377	5	11	452
Quality of Care (specific)	104	42	9	18	173
<i>Interpersonal style</i>	42	29	2	7	80
<i>Technical style</i>	62	13	7	11	93
Amenities and Services	69	18	3	0	90
Care After Death	12	15	4	2	33
Communication Domain					
Communication with Family	169	148	24	25	366
Coordination of Care	80	10	14	3	107
Value Mismatch Domain					
Being Present at Time of Death	41	58	17	18	134
Quantity of Care	32	24	17	5	78
Quality of Death	12	9	18	20	59
Total	578	701	111	102	1492

Findings

- Quality of Care (general) - most frequent theme for family members, 377 positive vs. 59 negative general comments.
 - Yet, when respondents are more specific, they shared more negative experiences. Out of all themes, nearly half the comments (n = 689) were examples of poor care.
 - Nurses and family members sometimes had different perceptions of EOL care quality.
 - Quality of Care: nurses made positive comments generally while family members shared incidents of poor care
 - Communication: nurses and family members mentioned this theme with similar frequency and balance between + and -.
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Findings

- This analysis found that while family members make general positive comments about the care of their loved ones, their specific examples are more likely to be about poor quality of care and negative experiences.
 - Nurses expressed frustrations with values mismatch in EOL care for their patients.
 - Families also raised this issue, but less often relative to other themes.
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Conclusions

- Our study confirms the findings of Breen et al., that clinicians frequently experience some form of conflict in ICU end of life care⁵.
- This conflict may be related to differences in perceptions between clinicians and families around EOL care.
 - While family members comment on a lack of quality of care, nurses perceive the quality of care to be positive and comment on values mismatches.

5. Breen, C.M. Conflict associated with decisions to limit life-sustaining treatment in intensive care units. *JGIM* 2001;Vol.16; 283-289

Conclusions

- Nurses and family members in this analysis shared dissatisfaction related to communication.
- Communication has been identified as key to quality end-of-life care but an area where clinicians lack skill^{6,7,8}.
- Curtis et al., identified communication with patients as one of three most frequently recognized EOL care domains in need of improvement⁹.

6. Lilly, G.M. An intensive communication intervention for the critically ill. *The American Journal of Medicine* 2000; Vol. 109; 469-475.

7. Curtis, J.R. Missed opportunities during family conferences about end-of-life care in the intensive care unit. *Crit Care Med* 2005; Vol 171;844-849.

8. Levy, M.M., McBride, D.L. End-of-life care in the intensive care unit: State of the art in 2006. *Crit Care Med* 2006, Vol. 34. No. 11 (Suppl.). S306-S08.

9. Curtis, J.R. Understanding physicians' skills at providing end-of-life care. Perspectives of patients, families, and health care workers. *J Gen Intern Med* 2001;16:41-49.

Insights

- These data offer the opportunity for nurses and others to hear the experiences of family members around EOL care in the ICU. This allows us to close the “quality loop” by identifying areas where EOL care can be improved.
 - These data also suggest where nurses and family members have disparate views of EOL care in the ICU. Focusing on where perceptions differ offers opportunities for dialogue with families to ensure high quality of care.
 - Skillful communication is critical for negotiating the values decisions that are embedded into EOL care in the ICU setting.
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Thank You!
