

Through the Eyes of Family and Nurses:

A closer look at end-of-life care in ICUs

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IPA Integrating
palliative
and
CC critical
care

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Problem

Challenges with end-of-life in the ICU include:

(Statement of the 5th International Consensus Conference in Critical Care: Brussels, Belgium, April 2003)

- ❑ Variability in practice
- ❑ Inadequate predictive models for death
- ❑ Elusive knowledge of patient preferences
- ❑ Poor communication between staff and surrogates
- ❑ Insufficient training of health-care providers
- ❑ The use of imprecise and insensitive terminology
- ❑ Incomplete documentation in the medical records

Research

- Approximately 20% of all Americans will die in an intensive care setting. (Angus, Crit Care Med, 2004)
 - ~ 4.4 million Americans are admitted to an ICU each year
 - ~ 12-17% of patients admitted to an ICU will die there (www.qualitymeasures.ahrq.gov)
 - The IPACC survey is being conducted at 13 community hospitals in the Pacific Northwest
 - 855 family members of dying ICU patients and 1028 nurses were surveyed
 - 2737 anonymous comments from the completed surveys were analyzed
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Purpose

- What do intensive care nurses need to be aware of when working with patients and their family at the end of life?
 - What can we as nurses do to ensure that dying patients and their families receive the care they desire?
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Methods

- Qualitative Data Analysis
 - Identified recurring themes
 - Designed codes and descriptions for themes
 - Atlas.ti (analysis software program) used to document and analyze coded quotes
 - Literature Review
 - Comparing and contrasting similar studies
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Examples of Codes

Code	Full Name	Description
CAT-N	Care Team-Negative	Large and complex team. Small and understaffed team. Family was not seen as part of the care team or did not regard itself as part of care team.

CAT-N Example Quotes

- “I did not have adequate information on the FloLan system* of care when it was started. It threw me into the primary care role without knowing all about the product. No one had contacted me before it was started. I was completely overwhelmed at that point. I questioned my ability to prepare & administer the product.” [Family member]
 - “The family & I repeatedly took alcohol swabs or packets out to the nurses station & re-iterated his allergy to it to the staff.” [Family member]
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Conclusion: Two Separate Roles

- Family Members are **Care-Givers** but:
 - They often feel out of place in this role
 - Their choice of treatment often conflicts with care staff
 - They are not offered training in:
 - Care-team approach
 - Procedures
 - Being a surrogate decision-maker
 - Family members are **Cared-for** but:
 - Their needs are not always met
 - Their needs can conflict with health care staff ideas
 - Their needs can conflict with patient needs
 - They could have conflicting emotions because of dual-role
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Examples of Codes

Code	Full Name	Description
CPROC-P	Choice of Procedure – Positive	All possible was done. The outcome was satisfactory.

CPROC-P Example Quotes

- “We tried our best to attend to this family and help them have everything done exactly as they wanted. Their needs were complex or confusing at times but I think we all worked to get things right.” [Nurse]
 - “Our family was comforted by the observation that everyone in ICU was doing everything they could to diagnose and treat my brother.” [Family member]
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Conclusions

- Nurses' viewpoint:

- This notion of “doing all that was possible” has to be directed at the family as well as at the patient
 - Patient: comfort care as well as procedures to extend life
 - Family: sees loved one in comfort and that the procedures are making a difference in extending life

- Families' viewpoint:

- Health care team collaborates in order to make the best decisions in treatment for patient. Team still takes time to comfort the family.
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Insights

- Further research needed on:
 - How to education family members to be part of the care-team in this complex (two role) way.
 - The conflicting emotions that could arise from having this dual-role.
 - How to education nurses to prepare family members for their roles.

 - Meeting families' needs
 - After the patient's death, the family is left with the memory of the death. If the family feels that the patient was well cared for, this may give them a sense of comfort.
 - Families also need to feel cared for when they experience the loss of a loved one in the ICU.
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Thank You!
