

The influence of the pediatric
intensive care unit (PICU)
culture on
end-of-life decision making



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Research Question

What influence(s) does the pediatric
critical care culture have on end-of-
life decision making?

Research Design

- Focused ethnography
- Purposive sample of 17 participants (11 RNs & 6 MDs) from Canadian PICUs with experience in caring for dying children and their families

Research Design (cont'd)

- Data collection conducted through semi-structured interviews (4 in-person & 13 telephone interviews)
- Analysis of semi-structured interviews focused on identifying cultural values and perspectives by comparing PICU cultures and the processes surrounding end-of-life decision making

Findings

The culture of PICU:

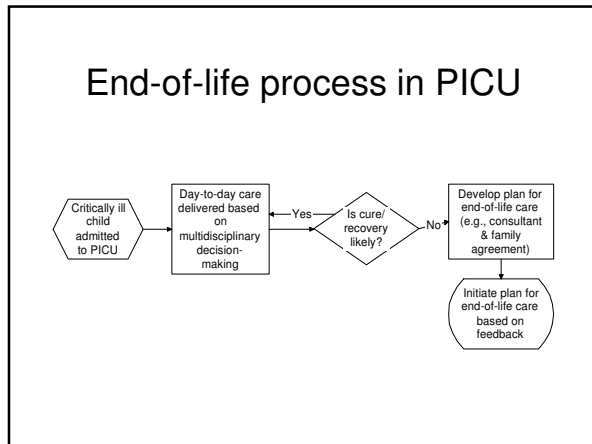
We're not called critical care without a reason. We're critical of ourselves and we do critical care work. And people feel bad when we can't cure the kids.

Control of actual or potential disorder in a high technology, high stress environment, with a goal towards making kids better.

Findings (cont'd)

End-of-life decision making in PICU:

End-of-life decision making is a very complex topic because it has many, many links with practice, also with individual values... what you value about life, death, nursing, the medical profession, and I find that each case is unique.



Discussion

I think one of the hardest things we have in PICU is to give up on the technology and the intensive part of it. And, to work intensively to make the death as good as possible, and as happy as possible.

Influence of a medical model of care on end-of-life decision making

- Power relationships between nurses and physicians
- Little evidence of “teamwork”
- Insignificance RNs placed on their roles in end-of-life decision making
- Need to plan end-of-life care

Belief that physicians break “bad news”

- Physician primary communicator in end-of-life discussion with families
- Presentation of “the plan” built upon a framework but tailored
- Nurses described feeling constrained in their end-of-life decision making role

Family-centred care & its influence on end-of-life decision making

- Actualization of family centred-care difficult due to conflict between culture of control/protecting and culture of partnering

Influence of the “silent voice” on end-of-life decision making

- Little evidence of children being consulted about their perspectives
- Legislation reported to take priority over the child's moral agency

Beliefs about how dying should occur

- Goal of a "good death"
- Dying process should be dignified, peaceful, pain & anxiety free, and quick

Beliefs about quality of life & its influence on end-of-life decision making

Participants described:

- a link between futility and quality of life
- the anticipated neurological outcome as important in decision making
- feeling conflicted about pursuing futile care

Influence of caregiver distress in end-of-life decision making

Distress attributed to:

- witnessing the *suffering* of dying patients
- observing the marked distress of family members
- experiencing a breakdown in relationships with the family or health care members

Beliefs surrounding protection in end-of-life decision making

- Nurses were strongly motivated to protect families and children from suffering
- Nurses described taking direct action to protect co-workers

Limitations of this study

- Limited scope
- Absence of direct observation
- Conducting research from an insider's perspective

Significance of the study

- Findings provide important insights about how values and beliefs influence end-of-life decision making in PICU
- Many questions for further study have been generated from this study...

*Is it possible for the current pediatric
critical care culture to think of dying in
another way?*