

Parents' Perspectives on Components of Quality Pediatric End-of-life Care

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Background

Quality end-of-life care is the right of every Canadian as stated by the Senate of Canada.¹ Quality end-of-life care is important to the dying child as well as to short and long-term health outcomes for parents, siblings, and extended family members.

Purpose

To identify the components of quality pediatric end-of-life care from the perspective of parents.

Methods

- Systematic review of research on parent perspectives of care provided to dying children and their families
 - 67 papers from 51 studies included
 - 5 key components of quality pediatric end-of-life care
- Focus groups to validate and extend lit review findings
 - 3 groups held
 - 10 bereaved parents participated

Focus Group Participants

- Parent Characteristics
 - 8 mothers, 2 fathers
 - Mean age 44.5 years (range 38 - 51y)
 - 6 married, 2 widowed, 2 separated
 - 8 anticipated child's death for at least 1 month
 - Time since child's death: Mean 5 years (range 1 - 18 y)
- Child Characteristics
 - 7 girls, 3 boys
 - Mean age 5 years (range 5d - 15y)
 - 4 cancer, 5 congenital illness, 1 neuromuscular condition
 - Location of death: 5 critical care, 5 home

Key Components

Connect with Families

- Sensitive, compassionate health professionals with good communication skills
- Individualized care

"[My daughter] doesn't even have a name. I don't even have a name. [The doctor] was so disconnected from my daughter...my daughter's life was in her hands."

Involve Parents

- Seek out and respect parent views/wishes
- Support and strengthen parent role

"One nurse ...was the one who did things with her that I never got a chance to do. She would touch her and she changed her. The first time we held her was when they had removed her from life support."

Alleviate Suffering

- Anticipate, assess and treat suffering in child and family
- Offer options and opportunity to fulfill wishes

"The opportunity [was] provided for us to be with [our daughter] when she took her final breath. As many tubes and stuff that she was all tied up into, it was done with great sensitivity, it was done at our own pace. We had an opportunity to bathe her...take little footprints of her... those [memories] are timeless for us now."

Share Information

- Give complete, truthful and consistent information that includes the "big picture" and possibility of death
- Share information among health professionals

"My husband decided to go back to the hospital and get [some supplies]... He wasn't there when she died. I think, in retrospect, if they had told us how close she was to dying, he could have been there. It was a huge regret for him."

Provide Bereavement Care

- Offer continued contact with family
- Provide information on grief and community resources

"Our experience was zero follow-up at all. Even from the incredibly, expensively well supportive team. No grief counselling even."

Conclusion

- Key components of quality pediatric end-of-life care are evident from the literature and parents' reports.
- A method of assessing the presence of these key components of care is needed.

Next Steps

- Use key components to develop an instrument to measure quality of pediatric end-of-life care from parents' perspective.
- Conduct content and face validity testing of instrument with health professionals and bereaved parents.
- Administer instrument through mailed survey from multiple pediatric health centres across Canada.
- Conduct psychometric testing of instrument.

Reference

1. Subcommittee of the Standing Senate Committee on Social Affairs, Science, and Technology. (2000). *Quality end-of-life care: The right of every Canadian*. Ottawa, ON: Senate of Canada.

Acknowledgements

Kimberley's doctoral work is supported by:

- Fellowship, Canadian Institutes for Health Research
- Career Enhancement Program, Canadian Child Health Clinician Scientist Program
- Sigma Theta Tau Scholarship, Canadian Nurses Foundation
- Mildred Claire Pratt Graduate Nursing Fellowship, Lawrence S. Bloomberg Faculty of Nursing
- The Innovation Fund in Children's Palliative Care Research, The Hospital for Sick Children

Special thank you to the parents who took part in the focus groups and shared their experiences and stories of their amazing children. It was truly an honor to meet you.