



Benefits to Understanding End of Life Decision Making in Pediatric Oncology

By Hope Nail-Bergin, Student Nurse

Baylor University Louise Herrington School of Nursing



“End-of-Life Care Preferences of Pediatric Patients With Cancer”

- Qualitative Descriptive Research
- 20 participants – Pediatric Oncology Units of hospitals located in Tennessee and Australia
- IIIB Level of Evidence – Johns Hopkins Evidence Scale
- ❖ The relevance and cognitive understanding of a child taking part in their own end-of-life decision-making.
- ❖ Nurses and other healthcare professionals should not presume a child can not be involved in the end-of-life decision-making process regarding their care.

Hinds, P. S., Drew, D., Oakes, L. L., Fouladi, M., Spunt, S. L., Church, C., & Furman, W. L. (2005). End-of-life care preferences of pediatric patients with cancer. *Journal of Clinical Oncology*, 23(36), 9146-9154. <http://dx.doi.org/10.1200/JCO.2005.10.538>

“Considerations About Hastening Death Among Parents of Children Who Die of Cancer”

- Quantitative Descriptive Research
- 141 participants – telephone and face-to-face interviews from Massachusetts and Minneapolis
- IIIB Level of Evidence – Johns Hopkins Evidence Scale
- ❖ Compared the parents who had considered hastening death to those who had discussed hastening the death of their child.
- ❖ Pain, especially uncontrollable pain, was more influential in whether or not hastening death was considered or discussed.

Dussel, V., Joffe, S., Hilden, J., Watterson-Schaeffer, J., Weeks, J., & Wolfe, J. (2010). Considerations about hastening death among parents of children who die of cancer. *Archives Of Pediatrics & Adolescent Medicine*, 164(3), 231-237. <http://dx.doi.org/10.1001/archpediatrics.2009.295>

Significance

Parents report end-of-life decisions to be the most difficult treatment-related decisions they face and clinicians perceive the assistance they can offer with these decisions to be inadequate (Hinds et al., 2005). Research offers patient, parents, and clinician’s perspectives as well as insight for nurses and other health care providers to implement standards of care and support throughout the process. Articles were located in CINAHL utilizing key words such as: pediatric oncology, end-of-life, palliative care, ethics, and oncology nursing. The Evidence in all five articles was graded using: The Johns Hopkins Evidence-Rating Scale. (Newhouse, Dearholt, Poe, Pugh & White, 2007).

“Parent-Clinician Communication Intervention during End-of-life Decision Making for Children with Incurable Cancer”

- Mixed Quantitative & Qualitative Descriptive Research
- 62 participants – Intensive Care and Bone Marrow transplant units at St. Jude Children’s Research Hospital, Tennessee
- IIIB Level of Evidence - Johns Hopkins Evidence Scale
- ❖ End-of-Life Communication Intervention (specially designed, open-ended questionnaire for the patient’s chart) played a key role improving the communication regarding end-of-life decision-making, satisfaction outcomes, and role fulfillment for the parents, nursing staff, and clinicians participating in the child’s care.

Hinds, P., Oakes, L., Hicks, J., Powell, B., Srivastava, D., Baker, J., & Furman, W. (2012). Parent-clinician communication intervention during end-of-life decision making for children with incurable cancer. *Journal Of Palliative Medicine*, 15(8), 916-922. <http://dx.doi.org/10.1089/jpm.2012.0006>

“Trying to Be a ‘Good Parent’ As Defined By Interviews With Parents Who Made Phase I, Terminal Care, and Resuscitation Decisions for Their Children”

- Qualitative Descriptive Research
- 62 participants – Intensive Care and Bone Marrow transplant units at St. Jude Children’s Research Hospital, Tennessee
- IIIB Level of Evidence – Johns Hopkins Evidence Scale
- ❖ The formal definition of being a ‘good parent’ to a child was descriptively identified.
- ❖ Specific nursing strategies help fulfill the ‘good parent’ definition and help the parents take comfort after the child is gone.

Hinds, P., Oakes, L., Hicks, J., Powell, B., Srivastava, D., Spunt, S., & Furman, W. (2009). “Trying to be a good parent” as defined by interviews with parents who made phase I, terminal care, and resuscitation decisions for their children. *Journal Of Clinical Oncology*, 27(35), 5979-5985. <http://dx.doi.org/10.1200/JCO.2008.20.0204>

“Decision Making by Parents of Children With Incurable Cancer Who Opt for Enrollment on a Phase I Trial Compared With Choosing a Do Not Resuscitate/Terminal Care Option”

- Qualitative Descriptive Research
- 62 participants – Intensive Care and Bone Marrow transplant units at St. Jude Children’s Research Hospital, Tennessee
- IIIB Level of Evidence – Johns Hopkins Evidence Scale
- ❖ Compared the ‘good parent’ definition amongst parents who chose differing treatment options.
- ❖ Nursing and healthcare staff support of parents’ end-of-life decisions was influential on when and how decisions were made and the role fulfillment of being a ‘good parent’.

Maurer, S., Hinds, P., Spunt, S., Furman, W., Kane, J., & Baker, J. (2010). Decision making by parents of children with incurable cancer who opt for enrollment on a phase I trial compared with choosing a do not resuscitate/terminal care option. *Journal Of Clinical Oncology*, 28(20), 3292-3298. <http://dx.doi.org/10.1200/JCO.2009.26.6502>

Summary

Each of the five articles contributed to a limited body of knowledge surrounding improving satisfaction outcomes in pediatric end-of-life care decision-making. As a nurse, it is our role to understand the wishes of the patient and their family in order to advocate for them with the rest of the healthcare team, as necessary, to improve satisfaction outcomes and plan patient care accordingly. Hinds et al.’s (2012) study confirms that using a communication intervention helped to improve overall communication amongst the parents and clinicians throughout the decision-making process and may have provided some comfort to the parents after the death of their child as it helped them to fulfill their role of being a ‘good parent’. This study demonstrated that there is an evidenced-based need for a communication intervention that nurses can use to help facilitate communication in end-of-life decision-making, plan patient care, and provide support to the patient and their family to improve satisfaction outcomes during this difficult time.

