

See page 190 for details about a podcast interview with the author of this article.

Conceptual Framework for the Study of Parental End-of-Life Decision Making in Pediatric Blood and Marrow Transplantation

Cindy J. Rishel, RN, BSN, OCN[®]

Blood and marrow transplantation (BMT) is an aggressive medical treatment associated with high morbidity and mortality. Survival rates for BMT vary from 25%–50%, depending on the underlying diagnosis and type of transplantation performed (Barrera, Boyd-Pringle, Sumbler, & Saunders, 2000; Drew, Goodenough, Maurice, Foreman, & Willis, 2005; Kolb, Gidwani, & Grupp, 2006). Despite the statistics, BMT often represents the most viable treatment option for children with certain types of life-threatening cancers, bone marrow failure, metabolic disorders, or immunodeficiency syndromes. Many children receiving BMT have endured lengthy, aggressive treatment only to suffer disease relapse or experience failure of more conventional treatment. Throughout an often prolonged course of disease, parents of children receiving BMT are forced to make numerous treatment decisions with the intent and hope of saving their child's life (Stevens & Pletsch, 2002). When curative efforts fail, parents suddenly are faced with decisions that focus on end-of-life treatment and care for their dying child.

Authors who have addressed parental end-of-life decision making for children have focused on parental priorities for end-of-life care, the meaning of end-of-life decision making for parents, the challenge of decision making involving palliative treatment with potentially toxic medications as opposed to supportive care alone, and the degree and type of control parents express throughout the decision-making process (Hinds et al., 2000, 2001; Meyer, Burns, Griffith, & Truog, 2002; Pyke-Grimm, Degner, Small, & Mueller, 1999; Sharman, Meert, & Sarnaik, 2005; Tomlinson et al., 2006). For this article, parental end-of-life decision making is defined as a parent's decision to not resuscitate or withdraw life-sustaining therapy to allow the terminally ill child to die a natural death.

Parents have consistently reported that end-of-life decisions are the most difficult they have faced on behalf

Purpose/Objectives: To describe a conceptual framework that will facilitate research and practice concerning parental end-of-life decision making in pediatric blood and marrow transplantation (BMT).

Data Sources: A review of relevant literature from Ovid[®], CINAHL[®], EBSCO, MEDLINE[®], PsycINFO, and various sociology and theology databases was combined with experiential knowledge.

Data Synthesis: The method of concept and theory synthesis and derivation as described by Walker and Avant was used in the development of this framework.

Conclusions: Use of the proposed conceptual framework is expected to provide the organization necessary for thinking, observation, and interpretation of parental end-of-life decision making in pediatric BMT.

Implications for Nursing: The ability to describe the process of parental end-of-life decision making in pediatric BMT will help nurses to provide appropriate counseling, education, and support for these children and their families at the end of life. In addition, the process will help nurses to promote the well-being of the children's families after end of life.

of a seriously ill child (Hinds et al., 1997; Hinds, Schum, Baker, & Wolfe, 2005) and, in retrospect, they express regret, doubt, and second guessing over the decision (Drew et al., 2005; Meyer et al., 2002). BMT is recognized as a particularly aggressive treatment that is delivered in an environment of semi-isolation. Children who die following BMT usually do so in the hospital after a prolonged stay, punctuated by numerous treatments and procedures (Hinds, Schum, et al., 2005). The transition from aggressive curative care to palliative care often is abrupt (Meyer et al., 2002). The parental decision to forego or withdraw life support for a dying child following BMT is the ultimate final decision and may occur from hours or even minutes to several days or longer prior to the child's death (Drew et al., 2005).