

Influences on decision-making indentified by parents of children receiving pediatric palliative care

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BACKGROUND: Parental decision making is a critical component in the provision of palliative and end-of-life care, yet factors that parents perceive as influencing this process, when they are making decisions for their children, have not been well characterized.

METHODS: As part of a mixed-methods cohort study, we interviewed 73 parents of 50 pediatric patients who were referred to the hospital's pediatric palliative care service. The semistructured interviews focused on “decision making for your child”; the interviews were recorded and transcribed. A random sample (n = 13) was first coded and analyzed for core themes, and these themes were then cross-validated with a second random sample (n = 3) of interviews.

RESULTS: Four dominant interrelated themes permeated parents’ discussions about the decisions they were making for their children and the process of decision making. First, Orientation and Direction (including the subthemes of Goals and Hopes, Spirituality and Meaning, and Purposeful Effort) connotes the parents’ effort to establish and clarify the broad context of decision making. Second, Defining What Is Good for the Child (including the subthemes of Quality of Life and Suffering, and Normalcy and Normalization) conveys how the parents posed questions and pondered what decisions would be in the child's best interests. Third, the entwined theme of Relationships, Communication, and Support reflects how parents reported the social and interactive nature of decision making. Fourth, the theme of Feelings and Personal Accountability focuses inward as parents report efforts to deal with their emotional responses and self-judgments.

CONCLUSIONS: Parents report grappling with several influences upon their decision-making processes that extend well beyond the standard discussions of medical information exchanges and the evaluation of risks and benefits. Decision support for these parents should account for these diverse influences.

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