Parental Sources of Support and Guidance When Making Difficult Decisions in the Pediatric Intensive Care Unit

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OBJECTIVE: To assess sources of support and guidance on which parents rely when making difficult decisions in the pediatric intensive care unit and to evaluate associations of sources of support and guidance to anxiety, depression, and positive and negative affect.

STUDY DESIGN: This was a prospective cohort study of 86 English-speaking parents of 75 children in the pediatric intensive care unit at The Children's Hospital of Philadelphia who were hospitalized greater than 72 hours. Parents completed standardized instruments and a novel sources of support and guidance assessment.

RESULTS: Most parents chose physicians, nurses, friends, and extended family as their main sources of support and guidance when making a difficult decision. Descriptive analysis revealed a broad distribution for the sources of support and guidance items related to spirituality. Parents tended to fall into 1 of 2 groups when we used latent class analysis: the more-spiritual group (n = 47; 55%) highly ranked “what my child wants” (P = .023), spouses (P = .002), support groups (P = .003), church community (P < .001), spiritual leader (P < .001), higher power (P < .001), and prayer (P < .001) compared with the less-spiritual group (n = 39; 45%). The more-spiritual parents had greater positive affect scores (P = .005). Less-spiritual parents had greater depression scores (P = .043).

CONCLUSIONS: Parents rely most on physicians, nurses, and friends and extended family when making difficult decisions for their critically ill child. Respondents tended to fall into 1 of 2 groups where the more-spiritual respondents were associated with greater positive affect and may be more resistant to depression.

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