Regoaling Over Time Among Parents of Children with Serious Illness: A Prospective Cohort Study (TH346-B)

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Objectives

• Describe prominent good parent beliefs among parents of children with serious illness.
• Describe the “regoaling” model of psychological adaptation to adversity and how this model is relevant to the good parent beliefs data and to palliative care practice.

Original Research Background: Parents’ beliefs about what they need to do to be a good parent when their children are seriously ill influence their medical decisions, and better understanding of how these beliefs change over time may improve decision support.

Research Objectives: To assess changes in parents' perceptions regarding the relative importance of 12 good parent attributes during 12 months of follow-up.

Methods: Prospective cohort study, with baseline discrete choice experiment in a sample of 200 parents of children with serious illness treated at a children's hospital, and follow-up at 4, 8, 12, and 16 months, assessing whether parents had changed their beliefs about what they felt they needed to do to be a good parent for their child.

Results: At the baseline interview, the top ranking good parent attribute was “Making sure that my child feels loved,” followed by “Focusing on my child's health,” “Making informed medical decisions,” and “Advocating for my child.” During the study 24 children died. By the 4-month follow-up, 40% of parents reported having a new goal among their top five goals, while 19% reported changing the order of their top five goals. During the interval from the prior assessment to 8-month follow-up, 27% reported new goals and 19% a new order; for the 12-month follow-up, 26% reported new goals and 24% a new order. Cumulatively, during the first 12 months of follow-up, 50% of parents reported new goals and 22% a different order of importance, while 28% of parents had not changed their beliefs about what the most important goals were for themselves.

Conclusions: Most parents of children with serious illness substantially change their beliefs of what they need to do to be a good parent over time.

Implications for Research, Policy, or Practice: Decision support for parents of children with serious illness should anticipate and accommodate shifting individual beliefs about being a good parent over time.