Brief Report

Parental Concordance Regarding Problems and Hopes for Seriously Ill Children: A Two-Year Cohort Study

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Abstract

Context. Parents of a seriously ill child may have different concerns and hopes for their child, and these concerns and hopes may change over time.

Objectives. In a mixed-method prospective cohort of parental dyads of children with serious illness, to describe the major problems and hopes perceived for their child, examine the degree of concordance between parents, and assess whether prevalence and concordance change over time.

Methods. Eighty-four parents (42 dyads) of seriously ill children reported the major problems and hopes for their children at baseline. Thirty-two parents (16 dyads) answered the same questions at 24 months. Problems and hopes were classified into nine domains. Observed concordance was calculated between parents on each domain. Data for parents of 11 children who died are reported separately.

Results. The most common major problem and hope domains at baseline were physical body, quality of life, future health and well-being, and medical care. Parental dyads demonstrated a moderately high percentage of concordance (69%) regarding reported problem domains and a slightly lower percentage of concordance on hopes (61%), with higher concordance for more common domains. Domain prevalence and concordance changed considerably at 24 months. Parents of children who later died showed markedly different patterns of domain prevalence and more extreme patterns of concordance.

Conclusion. Parents of children with serious illness may have different perspectives regarding major problems and hopes, and these perspectives change over time. Parents of sicker children are more likely to be in either complete agreement or disagreement regarding the problems and hopes they identify. J Pain Symptom Manage 2017;■:■−■. © *2017 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.*

Key Words
Pediatrics, serious illness, parental concordance, problems, hopes, decision-making

When children are seriously ill, parents often confront daunting health care decisions.[1−4] Parents base their decisions on multiple factors, including recommendations from doctors, personal beliefs about what a good parent ought to do, personal values, beliefs about the child's most urgent problems, and their hopes for their child's future.[5−11] When two parents (or other adults responsible for medical decision-making for the child) are involved in a child's care, the parents ideally make decisions in a collaborative manner both with clinicians and with each other.[12−16]

Although the degree to which parents and clinicians perceive a sick child's situation in similar terms has been studied,[17−22] less is known about the degree to which parents agree with each other. One study of parents of children with long-term health conditions

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found that parents agreed substantially about the severity of the child's illness and the child's unmet needs,[18] whereas another study of parents of children with advanced cancer found that parents may differ regarding perceptions of the child's quality of life and the importance of hope, anticipated quality of life, and prolonged survival when making hypothetical medical decisions.[23] A retrospective study of parents of children who died of cancer found that parental agreement on primary goals of care changed from diagnosis to end of life, and that lower levels of agreement were associated with higher levels of parental perception that the child had suffered.[24]

Believing that the lack of concordant perceptions between parents about a child's medical problems and their hopes for the child can strain both the parental relationship and the decision-making process[23]—and that this strain might be modifiable—we sought to improve our understanding of how parents view their child's serious illness. We previously reported on a cross-sectional study of parents of children receiving palliative care services that found that parents showed higher levels of concordance on reported problems experienced by the child than on reported hopes for the child.[19]

In this study, we expanded our focus to include a broader range of parents whose children were seriously ill and sought to 1) examine the prevalence of problems and hopes, 2) describe patterns of concordance between parents regarding major problems and hopes for their child, and 3) study how these patterns change over time, as this area has not been systematically examined. Although one study of parents of children with difficult to treat cancer found that the parents' hopes for their children changed over time as the children's conditions changed,[25] and a retrospective study found that parents reported different levels of concordance on treatment goals at diagnosis versus the end of life,[24] no studies have examined whether concordance between parents on perceived major problems and hopes changes over time.

Methods

Study Design and Participants

Participants were parents of seriously ill children in the Decision Making in Serious Pediatric Illness study, a mixed-method prospective cohort study on parental decision-making for children with serious illness conducted at The Children's Hospital of Philadelphia from September 2010 to December 2014. The hospital's Committee for the Protection of Human Subjects approved the protocol for this study.

Parents were defined as the adults who had primary decision-making responsibilities for the index patient, and included biological parents, adoptive or foster parents, and members of the extended family. Parents were eligible if their children were patients at The Children's Hospital of Philadelphia; had been admitted to the Pediatric Intensive Care Unit, Neonatal Intensive Care Unit, Cardiac Intensive Care Unit, or had been referred to the Pediatric Advanced Care Team for palliative care services; if the patient's attending physician thought that the patient had a serious illness and the parents would likely have to make a major medical decision in the next 12–24 months; if their children were not able to make medical decisions because of age or impaired cognitive capacity; and if the parents spoke English. Most parental dyads consisted of a mother and a father, but one dyad included two mothers, one dyad included a mother and a grandmother, and one dyad included a mother and a step-mother. Parents were not eligible if the parents were deemed by the physician to be emotionally overwrought by the clinical situation, did not speak English, or had lost custody rights; or if the child had died, had been discharged, had experienced a nonaccidental injury, or (to accommodate the longitudinal design of the study) if the physician thought the child might die within a month or less. Parents were asked to complete a one hour interview at baseline and a 20 minute interview at 24 months. Additional details about recruitment have been reported previously.[8]

Measures and Interviews

Parents were asked at baseline to report demographic data. Information about the complex chronic conditions of the patients was obtained from medical records. As part of the interview at baseline and 24 months, parents spent 10 minutes answering two open-ended questions: "Please think of three major problems that bother your child," and "Please think of three major goals or hopes you have for your child." Each parent was interviewed separately. The interviewer wrote down up to three problems and three hopes mentioned by each parent. Baseline interviews took place in person at the hospital. Follow-up interviews were conducted either in person or by phone. One author (K. C.) and one research assistant conducted all interviews.

Problem and Hope Domains and Coding

We used an emergent codebook approach as recommended by Creswell[26] to code the problems and hopes reported by parents. We started with eight domains and definitions that had been used successfully to categorize problems and hopes reported by parents of palliative care patients in a previous study.[19] After reviewing a subsample of the data, we updated the definitions and added an additional domain (future health and well-being) to capture future oriented statements made by parents in the current sample.