

# Parental Hopeful Patterns of Thinking, Emotions, and Pediatric Palliative Care Decision Making

## *A Prospective Cohort Study*

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**Objective:** To test the hypothesis that hopeful patterns of thoughts and emotions of parents of pediatric patients receiving palliative care consultative services are related to subsequent decisions, specifically regarding limit of intervention (LOI) orders.

**Design:** Prospective cohort study.

**Setting:** Children's hospital and surrounding region.

**Participants:** Thirty-three pediatric patients receiving palliative care consultative services who did not have LOI orders at time of cohort entry and their 43 parental adults.

**Main Exposures:** Parental levels at time of cohort entry of hopeful patterns of thinking and emotions, in conjunction with perceptions about patients' health trajectories.

**Main Outcome Measure:** Enactment of an LOI order after entry into the cohort.

**Results:** During the 6 months of observation, 14 patients (42.4%) had an LOI order enacted. In adjusted analyses, higher levels of parental hopeful patterns of thinking were significantly associated with increased odds of enactment of an LOI order (adjusted odds ratio [AOR], 2.73; 95% confidence interval [CI], 1.04-7.22). Increased odds of LOI enactment were associated to non-significant degrees with lower levels of parental positive affect (AOR, 0.44; 95% CI, 0.17-1.12), higher levels of parental negative affect (AOR, 2.02; 95% CI, 0.98-4.16), and parental perceptions of worsening health over time (AOR, 1.72; 95% CI, 0.73-4.07).

**Conclusion:** For pediatric patients receiving palliative care consultative services, higher levels of parents' hopeful patterns of thinking are associated with subsequent enactment of LOI orders, suggesting that emotional and cognitive processes have a combined effect on medical decision making.

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**P**ARENTS OF CHILDREN WITH ADVANCED life-threatening conditions confront daunting medical decisions. One of the major decisions is whether to institute a limit of intervention (LOI) order for their child. In pediatric care for children with advanced life-threatening conditions, LOI orders typically address aspects of do-not-resuscitate orders and can also specify limitations on other medical interventions.<sup>1</sup> The intentions of such orders are to prevent suffering and promote comfort, quality of life, and dignity.<sup>2</sup> Pediatric palliative care programs routinely broach the topic with parents (and older patients) of the goals of further medical care and whether to pursue all possible interventions or whether to issue an LOI order. Yet despite the frequency of such discussions between clinicians and parents, little is known about how such crucial decisions are made. The Institute of Medicine and others have underscored the importance of un-

derstanding the parental decision to implement an LOI and more broadly the processes underlying decisions affecting a gravely ill child's medical care.<sup>3-5</sup>

Ethical guidance regarding how to make these decisions emphasizes a thorough and thoughtful consideration of potential benefits and harms of treatment options, seeking to determine what is in the child's best interest.<sup>2</sup> These guidelines, however, do not grapple with 3 cardinal features of the situation that envelops parents making crucial decisions with imperfect knowledge and under extreme stress. First, clinical experience suggests that children with life-threatening conditions experience variable health trajectories.<sup>3,6</sup> Even if a specific disease process is inevitably fatal, the individual duration and fluctuations in health over time are uncertain, ranging from rapid to slow declines in health or following a pattern of crises interspersed in periods of better health. Confronting decisions in the face of this uncertainty, parents may abandon

highly analytic ethical frameworks and be guided instead by psychological processes known to influence decision making.<sup>7-9</sup>

Second, parents report extreme emotions, both negative and positive, when their children are seriously ill.<sup>10-16</sup> Parental affect is influenced by how the child is faring and likely influences how parents perceive their child's health status, impacting medical decisions made on the child's behalf. People use feelings when making decisions, specifically regarding whether to seek additional information and whether to select a course of action based on the emotions it generates.<sup>17-19</sup> Individuals who have higher levels of positive affect are less likely to change the current status quo,<sup>20</sup> while those with higher levels of negative affect are more willing to pursue a different course of action.<sup>21</sup>

Third, parental hopeful patterns of thought may also shape medical decision making. While the concept of hope has many definitions, one useful operational definition considers hopefulness as a long-term individual trait, dependent on 2 categories of thoughts, the first about possible "pathways" toward achieving a goal, the second about an individual's "agency" or self-perceived ability to pursue a pathway or enact a plan.<sup>22,23</sup> With this construct of hope and a corresponding validated hope-measurement instrument, high-hope individuals have been found to have better outcomes after burn injuries, report a greater likelihood of engaging in cancer-prevention behaviors, and experience greater well-being, role functioning, and fewer symptoms after 12 weeks of individual psychotherapy.<sup>24,25</sup> Hope may also play a key role in coping with loss when a goal proves unattainable.<sup>26</sup> When discussing medical treatment options for life-threatening pediatric conditions, parents' specific hopes regarding their children and the care that their children receive are fundamental motifs, combining both thoughts and feelings about the current clinical situation and possible future outcomes.<sup>27,28</sup> Although specific hopes and broader hopeful patterns of thinking would seem to influence medical decision making, to our knowledge, this has yet to be studied within the context of medical decision making at the end of life.

We therefore conducted a prospective cohort study at our large children's hospital of patients receiving pediatric palliative care consultative services and their parents to test the hypothesis that parental hope, along with parental perceptions of the trajectory of the child's health and their positive and negative affect, would be associated with their decision to enact an LOI order during the 6 months after entry into the cohort.

## METHODS

### STUDY DESIGN AND PARTICIPANTS

The Decision Making in Pediatric Palliative Care Study, funded by the National Institute of Nursing Research, was a prospective 6-month cohort study that aimed in part to quantitatively assess the association between baseline parental cognitive and affective measures and subsequent medical decision making. The study was conducted at The Children's Hospital of Philadelphia, which provides a broad range of pediatric subspecialty care and has specialized intensive care units for neonatal, pediatric, and cardiac patients. Since 2003, The Children's Hospital of Philadelphia has

had a dedicated multidisciplinary team that provides pediatric palliative care consultative services and is active in the care of patients and families in the hospital and home settings. The hospital's Committee for the Protection of Human Subjects approved the protocol for this study.

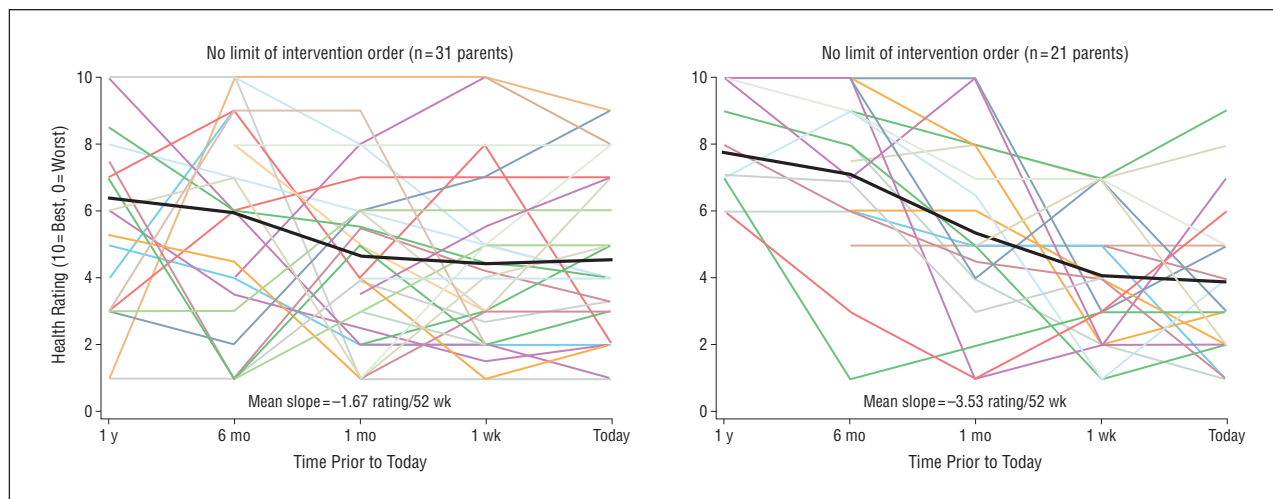
Between October 2006 and July 2008, parents of patients referred by generalist and subspecialty pediatric services for palliative care services at The Children's Hospital of Philadelphia were eligible to participate provided that the patient was younger than 18 years and did not make medical decisions or was 18 years or older but of impaired cognitive capacity and did not make medical decisions and that the parent(s) spoke English. Study exclusion criteria were the patient had already died or been discharged from the hospital or was actively dying; the patient had no associated parental adult or the parental adult was non-English speaking or was emotionally unstable; or the patient made his or her own medical decisions. For each patient, we enrolled 2 parental adults, or 1 if no other parental adult was available or willing to participate. Families of 88 patients met inclusion criteria and were approached and provided with complete information regarding the study. The families of 50 patients (62.5%) consented to participate. For the baseline assessment interview, participants received \$25 for time and effort to participate. Most parents participated in person, 17 parents (23.3%) participated by telephone, and 13 parents (17.8%) completed the surveys online. For the subsequent 6-month period of cohort observation, data were collected from electronic medical records.

### MEASURES OF PARENTAL AND PATIENT CHARACTERISTICS

Parent and patient demographic and clinical characteristics were ascertained by asking the parental adult. Parental adults rated their children's health at the time of the baseline interview on a 10-point visual analog scale from worst (1) and best (10) the child had ever been; they also rated retrospectively their children's health 1 week and 1, 6, and 12 months prior to the interview. Parents completed the previously validated Adult Dispositional Hope Scale, a 12-item instrument that assesses enduring patterns of thoughts regarding pathways (means or steps to achieve goals) and agency (personal efficacy to achieve goals).<sup>22</sup> This scale has performed well in a variety of populations, comparing favorably with other measures of either hope or the related construct of optimism.<sup>22,29</sup> The sample Cronbach  $\alpha$  was .69. Parents also completed the previously validated Positive and Negative Affect Scale, a 20-item instrument widely used in psychological research<sup>3</sup> with 10 descriptors for a positive affect scale and 10 descriptors for a negative affect scale; the parents reported how they felt during the past week. In this sample, the Cronbach  $\alpha$ 's were 0.83 (positive) and 0.88 (negative).

### LOI ORDER STATUS AND INCOMPLETE DATA

During the baseline data collection, the study team gathered information directly from the parents and the patients' medical records regarding whether the patients had any LOI order in place; in no instance did these sources of information disagree. Fourteen patients entered the study with LOI orders already in place; 36 patients, with 60 parents, did not have LOI orders. As the primary outcome measure, during the ensuing 6-month interval after study entry, the study team reviewed the patients' medical records (including hospitalizations, office or home visits, and telephone calls) to assess whether the patients had any changes in LOI orders. To be appropriately responsive to the circumstances of the participants, the protocol permitted the interviewer to curtail data collection if the par-



**Figure 1.** Parental health trajectory ratings of patients by subsequent change in limit of intervention order status. The thick black line in each graph represents the mean health rating for the group at each point. The mean slope was the mean of individual change in health rating value from the most distant rating to the rating given today divided by the number of weeks recalled and then multiplied by 52 weeks.

participant appeared to be burdened or distressed. Interviews were also interrupted on occasion by clinical events affecting the patient. Consequently, 17 of the 60 parents (28.3%) had incomplete data regarding affective and cognitive measures, and these parents were excluded from the primary analysis, along with 3 patients who no longer had a parent included in the primary analysis. Our primary analysis, therefore, was conducted on 33 pediatric patients and their 43 parents.

## STATISTICAL ANALYSIS

For our primary analysis, we first described the sample in terms of proportions, means, and medians. To compare proportions between groups we used the  $\chi^2$  or Fisher exact tests. We standardized the scores of the main predictor variables (baseline scores regarding health trajectory, parental positive and negative affect, and hope trait) as  $z$  scores. We assessed the association of the outcome (subsequent enactment of an LOI order) with each of the standardized main predictor variables using logistic regression modeling. We tested the adjusted multivariable associations between the outcome and the standardized main predictor variables in a single complete multivariable logistic regression model that accounted for clustering of parental observations by patients. We subsequently examined the effect of eliminating single predictor variables from the model in terms of the effect on the estimated associations and model fit ( $C$  statistic and the Akaike information criterion). In a sensitivity analysis, we used multiple imputation techniques to complete the missing affective and cognitive measures for the 17 parents who were omitted from the primary analysis and then reestimated the adjusted odds ratio using 10 sets of original and imputed data.<sup>30-32</sup> Statistical inferences were based on 2-tailed tests with  $\alpha$  at .05. All analyses were performed using Stata 11.0 (Stata-Corp, College Station, Texas).

## RESULTS

### CHARACTERISTICS OF PATIENTS AND THEIR PARENTAL ADULTS

Slightly more than half of the patients were female (58%). Mean (SD) age was 5.5 (5.5) years (range, 0.1-18 years). The majority of the children were white (76%). Nearly

half of the patients were in a hospital ward at the time of the interview (16; 48%), 11 (33%) were in the intensive care unit, and 6 (18%) were at home. Almost half of the children were covered by Medicaid (48.5%).

Patients with neuromuscular (24%) or metabolic (30%) diseases composed the majority. Other diseases included malignant tumors (21%), congenital malformations (18%), and respiratory (3%) and gastrointestinal (3%) diseases. Most patients were reported to have no role in their medical decisions (81.8%) either because of young age or impairment of cognitive capacity secondary to illness, while 18.2% were noted to have some role.

Parental reports of the patients' health status over time demonstrated substantially varied patterns of illness trajectories, ranging from steady downward trends or steep declines immediately before the interview, to patterns suggesting stable levels of health or even improvement over time (**Figure 1**).

Mothers composed the majority of parents identified as primary guardians in this study (78.8%). Six fathers (18%) were identified as primary guardians, and overall, 14 fathers participated in the study. Two other guardians (1 stepmother and 1 grandmother) were also included. Median age of the parents was 37 years, with an age range from 21 to 52 years. Most parents were white (35; 81.4%), 3 were black (7%), and 1 self-described as "other" (2.3%). Thirty-three parents were married (76.7%), 4 (9.3%) were single, and 5 (11.9%) were separated or divorced. Most parents had attended college (19; 50%) and/or graduate school (13; 34.2%).

During the 6 months children were followed up in the study, slightly less than half of patients had LOI orders enacted (14; 42.4%); of those with orders, 1 family rescinded the orders, and 2 families rescinded and then re-enacted the orders. Among the 16 patients (48%) who died during the 6-month period, 7 (43.8%) died at home, 5 (31.3%) died in the hospital intensive care unit, and 4 (25%) died in a hospital ward. Of the patients who died, 10 (62.5%) had an LOI order in place.

**Table 1. Child Characteristics by Parental Hope Score, Affective, and Health Trajectory Measures**

Child Characteristics	No. of Patients (n=33)	No. of Parents (n=43)	Hope Score		Negative Affect		Positive Affect		Health Trajectory	
			Mean (SD)	P Value	Mean (SD)	P Value	Mean (SD)	P Value	Mean (SD)	P Value
Age, y										
<1	7	10	26.4 (2.1)	.30	29.7 (6.9)	.03	33.7 (8.6)	.69	-0.4 (3.9)	.20
1-4	11	15	25.2 (3.3)		30.4 (10.8)		34.4 (9.0)		-3.9 (3.8)	
5-9	8	10	26.9 (2.8)		23.1 (8.1)		36.9 (5.6)		-2.0 (4.6)	
10-24	7	8	27.6 (2.1)		26.1 (9.6)		37.6 (5.4)		-2.5 (2.5)	
Sex										
F	19	23	26.0 (2.6)	.49	30.0 (9.9)	.14	35.6 (7.1)	.53	-3.2 (3.8)	.28
M	14	20	26.8 (3.0)		25.1 (8.1)		35.3 (8.3)		-1.4 (3.8)	
Race										
White	25	25	25.9 (2.8)	.51	28.6 (9.1)	.87	34.7 (7.2)	.51	-3.3 (3.9)	.13
Nonwhite	5	5	27 (4.2)		26 (9.7)		38 (5.4)		-2.0 (2.0)	
Insurance										
Private	15	22	25.9 (2.6)	.14	26.3 (7.8)	.20	34.5 (5.3)	.66	-3.1 (4.1)	.98
Medicaid	16	19	26.0 (3.7)		28.8 (11.0)		35.9 (8.2)		-2.7 (3.2)	
Other	2	2	28 (0.7)		34 (4.2)		36.5 (4.9)		0 (5.7)	
Location										
Not in hospital	6	7	26.2 (3.1)	.58	24 (10.4)	.25	33.3 (4.0)	.44	0.6 (2.4)	.10
Hospital ward	16	22	26.3 (2.7)		29.9 (9.6)		37.4 (7.7)		-2.7 (4.4)	
Intensive care unit	11	14	26.5 (3.0)		26.3 (8.2)		33.4 (8.2)		-3.4 (3.1)	
CCC										
Noncancer	26	36	26.3 (2.8)	.84	27.3 (9.9)	.95	35.2 (7.8)	.18	-2.3 (3.9)	.63
Cancer	7	7	26.6 (2.9)		29.9 (5.7)		36.7 (6.7)		-2.6 (4.2)	
Role in medical decisions										
Some role	6	6	27.9 (2.2)	.57	23.0 (5.2)	.03	37.5 (6.7)	.40	-2.9 (1.9)	.35
No role	27	37	26.1 (2.8)		28.5 (9.7)		35.1 (7.7)		-2.3 (4.1)	

Abbreviation: CCC, complex chronic conditions.

**Table 2. Parent Characteristics by Parental Hope Score, Affective, and Health Trajectory Measures**

Parent Characteristics	Total (n=43)	Hope Score		Negative Affect		Positive Affect		Health Trajectory	
		Mean (SD)	P Value	Mean (SD)	P Value	Mean (SD)	P Value	Mean (SD)	P Value
Age, y									
21-34	9	25.2 (2.6)	.30	33.3 (7.4)	.16	33.7 (5.8)	.92	-3.5 (3.9)	.61
35-38	14	25.8 (3.7)		27.3 (10.9)		34.8 (8.7)		-1.7 (4.0)	
39-66	15	27.4 (1.8)		24.8 (8.9)		36.2 (6.9)		-3.0 (2.7)	
Sex									
F	19	26.2 (3.2)	.31	27.8 (9.2)	.93	35.0 (7.0)	.94	-2.0 (4.1)	.92
M	14	26.5 (1.9)		27.6 (10.1)		36.4 (8.8)		-3.1 (3.4)	
Race									
White	35	26.2 (2.6)	.62	28.4 (9.5)	.79	34.5 (7.5)	.96	-2.8 (3.7)	.32
Nonwhite	4	26.4 (4.6)		28.3 (9.6)		38 (6.2)		-1.5 (1.9)	
Type									
Mom	27	26.0 (3.2)	.15	28.3 (9.3)	.47	35 (6.1)	.63	-2.2 (3.8)	.32
Dad	14	26.5 (1.8)		27.6 (10.1)		37.1 (9.4)		-2.4 (4.5)	
Other <sup>a</sup>	2	29.3 (0.4)		21.5 (2.1)		29 (12.8)		-4.4 (0.9)	
Education									
High school	6	23.9 (3.2)	.67	38.2 (5.1)	.01	35.3 (9.2)	.26	-3.6 (2.4)	.54
Some college	19	26.2 (2.7)		27.7 (9.4)		34.5 (6.6)		-3.0 (3.2)	
Some graduate school	13	27.5 (2.3)		24.2 (8.6)		35 (8.5)		-2.7 (3.9)	
Marital status									
Married	33	26.3 (2.7)	.92	28.0 (9.7)	.57	35.3 (7.6)	.88	-2.4 (4.2)	.24
Single	4	27.3 (4.1)		25.8 (10.9)		33.8 (11.3)		-0.5 (3.3)	
Divorced	5	25.9 (3.4)		30.4 (5.3)		37.6 (5.1)		-4.0 (1.4)	
Financial difficulties									
No	19	26.1 (2.9)	.62	27.1 (9.6)	.64	32.9 (8.5)	.87	-2.0 (3.9)	.14
Yes	18	26.2 (2.9)		28.5 (10.2)		37.1 (5.2)		-3.5 (2.7)	

<sup>a</sup>Other includes 1 stepmother and 1 grandmother.

**PARENTAL HOPE, AFFECTIVE, AND HEALTH TRAJECTORY MEASURES**

Parents reported a mean (SD) hope score of 26.3 (2.8) at baseline (which is similar to a sample of nurses at a children's hospital<sup>33</sup>) and high scores (compared with

studies of healthy and chronically ill populations<sup>34-37</sup>) for negative (mean [SD], 27.7 [9.4]) and positive (mean [SD] 35.4 [35.4]) affect. Higher hope scores were positively correlated with positive affect (0.38;  $P=.01$ ) and negatively correlated with negative affect (-0.28;  $P=.07$ ), while positive and negative affect were not substantially cor-



**Table 3. Patient and Parent Characteristics by Limit of Intervention Order Status**

	No. (%)				P Value
	Change in Limit of Intervention Order Status				
	Sample Size	No Change (n=19)	Sample Size	New Order (n=14)	
<b>Children</b>					
Age, y					.81
<1	19	3 (15.8)	14	4 (28.6)	
1-4	19	6 (31.6)	14	5 (35.7)	
5-9	19	5 (26.3)	14	3 (21.4)	
10-24	19	5 (26.3)	14	2 (14.3)	
Sex					.72
F	19	10 (52.6)	14	9 (64.3)	
M	19	9 (47.4)	14	5 (35.7)	
Race					.36
White	17	13 (76.5)	13	12 (92.3)	
Nonwhite	17	4 (23.5)	13	1 (7.7)	
Insurance, private	19	9 (47.4)	14	6 (42.9)	.55
Medicaid	19	8 (42.1)	14	8 (57.1)	
Other	19	2 (10.5)	14	0	
Location					.64
Not in hospital	19	4 (21.1)	14	2 (14.3)	
Hospital ward	19	10 (52.6)	14	6 (42.9)	
Intensive care unit	19	5 (26.3)	14	6 (42.9)	
CCC					.42
Noncancer	19	16 (84.2)	14	10 (71.4)	
Cancer	19	3 (15.8)	14	4 (28.6)	
Role in medical decisions					>.99
Some	19	3 (15.8)	14	3 (21.4)	
No role	19	16 (84.2)	14	11 (78.6)	

	No. (%)				P Value
	Change in Limit of Intervention Order Status				
	Sample Size	None (n=27)	Sample Size	New (n=16)	
<b>Parents</b>					
Age, y					>.99
21-34	23	5 (21.7)	15	4 (26.7)	
35-38	23	9 (39.1)	15	5 (33.3)	
39-66	23	9 (39.1)	15	6 (40)	
Gender					.51
F	27	17 (62.9)	16	12 (75)	
M	27	10 (37)	16	4 (25)	
Race					>.99
White	24	21 (87.5)	15	14 (93.3)	
Nonwhite	24	3 (12.5)	15	1 (6.7)	
Type					.56
Mom	27	14 (51.9)	16	11 (68.8)	
Dad	27	9 (33.3)	16	3 (18.8)	
Other <sup>a</sup>	27	4 (14.8)	16	2 (12.5)	
Education					>.99
High school	22	3 (13.6)	16	3 (18.8)	
College	22	11 (50)	16	8 (50)	
Graduate school	22	8 (36.4)	16	5 (31.3)	
Marital status					.06
Married	26	20 (76.9)	16	13 (81.3)	
Single	26	5 (19.2)	16	0	
Divorced	26	1 (3.9)	16	3 (18.8)	
Financial difficulties					.74
No	23	11 (47.8)	14	8 (57.1)	
Yes	23	12 (52.2)	14	6 (42.9)	

Abbreviation: CCC, complex chronic conditions.  
<sup>a</sup>Other includes 1 stepmother and 1 grandmother.

related with each other (-0.11; P=.5). The mean (SD) score for the health trajectory was -2.4 (3.9), which indicates declining health over the preceding 52 weeks. These values did not differ based on child characteris-

**Table 4. Parental Hope Score, Affective, and Health Trajectory Measures and Limit of Intervention Order Status**

	Subsequent Limit of Intervention Order		
	Mean (SD)		Unadjusted OR (95% CI) <sup>a</sup>
	No (n=27)	Yes (n=16)	
Hope score	26.2 (2.6)	26.6 (3.2)	1.17 (0.52-2.64)
Positive affect	37.1 (5.3)	32.6 (9.8)	0.52 (0.22-1.25)
Negative affect	25.9 (9.7)	30.9 (8.1)	1.79 (0.91-3.51)
Worsening health trajectory <sup>b</sup>	-1.67 (4.23)	-3.53 (3.05)	1.75 (0.86-3.59)

Abbreviations: CI, confidence interval; OR, odds ratio.  
<sup>a</sup>Hope, positive affect, and negative affect measure values were standardized using z score.  
<sup>b</sup>Health trajectory scores decrease as the quality of life rating decreases; the OR reflects the association with a 1-unit decline in health.

tics (**Table 1**), with the exception of negative affect scores being higher among parents with younger children (P=.03) and with children who had no role in decision making (P=.03). Similarly, these scores did not differ based on parental characteristics (**Table 2**), with the exception of negative affect scores being higher for parents who reported less higher education (P=.01).

#### CHILD AND PARENT CHARACTERISTICS AND SUBSEQUENT LOI ORDERS

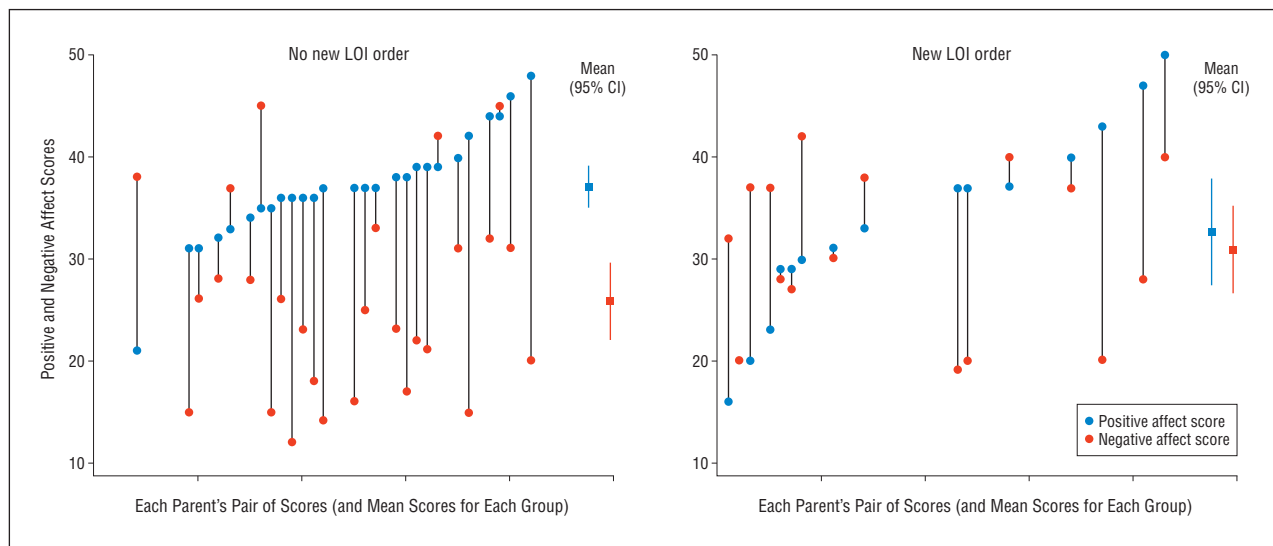
Baseline demographic and clinical characteristics of both children and parents were not significantly associated with subsequent decisions regarding enactment of LOI orders (**Table 3**).

#### PARENTAL AFFECTIVE AND HEALTH TRAJECTORY MEASURES AND SUBSEQUENT LOI ORDERS

In univariable analyses (**Table 4**), no statistically significant association was evident between subsequent LOI orders and parental baseline measures of the hope score (P=.70), positive (P=.15) or negative (P=.09) affect, or health trajectory (P=.13).

Parental ratings of the child's health trajectory during the year prior to the baseline interview, when categorized by the presence or absence of subsequent LOI orders (Figure 1), display substantial heterogeneity of patterns but suggest an overall steeper mean rate of perceived declining health among those patients who subsequently had an LOI order (mean slope of 3.53 decline per 12 months) than those who did not (mean slope of 1.67 decline per 12 month; comparison of slopes, P=.13).

Parental positive and negative affect scores, paired for each individual parent (**Figure 2**), demonstrate that the majority of parents reported higher positive affective scores than negative affective scores (31 vs 11 parents; 1 parent reported the same score for positive and negative affect). Parents whose children subsequently did not have an LOI order enacted reported



**Figure 2.** Parents' positive and negative affect scores by subsequent change in limit of intervention (LOI) order status. CI indicates confidence interval.

more positive than negative affect (mean 37.1 for positive affect score, 25.9 for negative affect score;  $P < .001$ ), whereas parents whose children subsequently did have an LOI order enacted reported equal levels of positive and negative affect (mean 32.6 for positive affect score, 30.9 for negative affect score;  $P = .61$ ).

In multivariable-adjusted analyses (**Table 5**), which reflect the interrelatedness of hope, affect, and thoughts regarding the child's perceived health trajectory, higher baseline parental hope scores were associated with subsequent LOI orders (adjusted odds ratio [AOR], 2.73; 95% confidence interval [CI], 1.04-7.22). Although not to statistically significant degrees, higher baseline levels of positive affect were associated with a reduced odds of subsequent LOI orders (AOR, 0.44; 95% CI, 0.17-1.12); higher baseline levels of negative affect were associated with an increased odds of subsequent LOI orders (AOR, 2.02; 95% CI, 0.98-4.16); and parental reports of a steeper declining health trajectory slope were also associated with an increased odds of subsequent LOI orders (AOR, 1.72; 95% CI, 0.73-4.07).

#### EXPLANATORY VALUE OF SUBSETS OF PARENTAL CHARACTERISTICS

To further assess the relationship among the various baseline measures on subsequent LOI orders, and the ability of sets of these measures to discriminate between patients who did and did not subsequently have LOI orders enacted, we repeated our primary multivariable-adjusted analysis with subsets of the measures (Table 5). In all the models, the general pattern of the direction of association between the measures and the outcomes was consistent, while varying in terms of the estimated sizes of the associations. The complete model with all the measures had the most discriminative power (as indicated by the largest of the C statistics), whereas the partial model that omitted the health trajectory score had nearly the same discriminative power and was the optimal parsimonious

model (as indicated by the lowest Akaike information criterion score).

#### POTENTIAL IMPACT OF INCOMPLETE DATA

To assess the potential impact of incomplete data, we imputed the values of the missing data and repeated our primary complete model multivariable-adjusted analysis (Table 5). With a total of 36 patients who did not have LOI orders at the time of study enrollment and their 60 parental adults, subsequent LOI orders were associated with higher baseline levels of hope score (AOR, 2.61; 95% CI, 1.10-6.14) and negative affect (AOR, 1.99; 95% CI, 1.08-3.67) and not significantly associated with positive affect (AOR, 0.57; 95% CI, 0.26-1.28) or with declining health trajectory (AOR, 1.99; 95% CI, 0.92-4.30).

#### COMMENT

During the course of 6 months of cohort follow-up, children with life-threatening conditions receiving palliative care consultative services were more likely to have an LOI order enacted if their parents had had higher hope scores at baseline, after adjustment for the parents' baseline measures of affect and perceptions of the child's health trajectory. At the time of entry into this cohort, the parents reported high levels of both positive and negative affect during the preceding week and had scores regarding hopeful patterns of thinking comparable with other reference groups. Additionally, parents' perceptions of their children's illness trajectories during the prior 12 months exhibited an overall trend of declining health but substantial heterogeneity of individual patterns, many marked by fluctuations in health over time. These observations present an empirically detailed and emotionally nuanced portrait of parental decision making for seriously ill children, raising important questions about how the processes of

decision making should be studied, understood, and supported.

Fundamentally, this study sought to deepen our understanding of the decision-making process regarding LOI orders, not to judge it. As pediatric palliative care clinicians, we approach the conversation about goals of care and possible limits of intervention with no agenda other than to help parents (and older patients) to explore the issues. Correspondingly, as researchers, we have approached the study of parental decision making from a position of equipoise, believing that LOI orders can reduce suffering and promote comfort but that they are not necessarily the appropriate decision for every pediatric palliative care patient.

The triad of findings regarding parental perceptions of health trajectory, positive and negative affect, and hopeful patterns of thought and their association with subsequent medical decision making can be provisionally explained with several previously described mechanisms. First, perceptions of declining health, in the context of an underlying disease that cannot be cured, may be the basis for a rational decision to enact an LOI order. The declining health trajectory may be prognostic of even worse health status in the future and the judgment that interventions that only offer the potential benefit of remaining in that worsened health status are no longer in the patient's best interest. Such thoughts may motivate parents and clinicians to engage in discussions and decisions regarding LOI orders. Additionally, since parents who perceived that their child's health was declining reported higher levels of negative affect, the impact of negative affect on subsequent decisions could be ultimately due to thoughts about the patient's best interests.

A second explanation focuses on the relationship between parental affect and their perceptions of the child's health trajectory and their decision-making processes. While the finding of high levels of both positive and negative affect may seem surprising, parents were reporting on their experience during the preceding week, and previous studies of persons' affect states over time have shown both types of affect to be common<sup>38</sup> and not diametrically opposed.<sup>39</sup> Quite importantly, individuals use their feelings as information, basing their appraisal of situations in part on the positive or negative feelings that they are experiencing at the time.<sup>40</sup> In a classic experiment, people rated their quality of life lower if they were in a transiently more negative mood because of poor weather that day.<sup>17</sup> A similar mechanism could result in parents who have higher levels of negative affect perceiving their child's health status to be in greater decline and those with higher levels of positive affect to view their child's health status more favorably. In addition to influencing how people appraise situations, negative affect can increase people's willingness to change the status quo, potentially shifting to a new set of goals, while positive affect can do the opposite.<sup>41-44</sup> Parents with higher levels of negative affect may be more apt to consider a change in the goals of care and the corresponding selection or limitation of interventions.

The third mechanism involves hopeful patterns of thinking. Perceiving feasible pathways toward desired

**Table 5. Limit of Intervention Order Status and Parental Hope Score, Affective, and Health Trajectory Measures<sup>a</sup>**

	No. of Parents	AOR <sup>b</sup> (95% CI)	AIC	C Statistic
<b>Complete model</b>				
Hope score	43	2.73 (1.04-7.22)	55.83	0.7685
Positive affect	43	0.44 (0.17-1.12)		
Negative affect	43	2.02 (0.98-4.16)		
Worsening health trajectory	43	1.72 (0.73-4.07)		
<b>Partial model without illness trajectory</b>				
Hope score	43	2.32 (0.99-5.47)	55.27	0.7616
Positive affect	43	0.42 (0.17-1.05)		
Negative affect	43	2.17 (1.07-4.40)		
<b>Partial model without hope score</b>				
Positive affect	43	0.58 (0.24-1.41)	58.04	0.7176
Negative affect	43	1.60 (0.82-3.14)		
Worsening health trajectory	43	1.36 (0.62-2.96)		
<b>Partial model without affect scores</b>				
Hope score	43	1.53 (0.58-4.06)	59.24	0.6539
Worsening health trajectory	43	2.03 (0.96-4.28)		
<b>Complete model with multiple imputation</b>				
Hope score	60	2.61 (1.10-6.14)	<sup>c</sup>	<sup>c</sup>
Positive affect	60	0.57 (0.26-1.28)		
Negative affect	60	1.99 (1.08-3.67)		
Worsening health trajectory	60	1.99 (0.92-4.30)		

Abbreviations: AIC, Akaike information criterion; AOR, adjusted odds ratio; CI, confidence interval.

<sup>a</sup>Hope, positive affect, and negative affect measure values were standardized as z scores.

<sup>b</sup>The AOR for each model was adjusted for only the other variables listed for each model.

<sup>c</sup>The AIC and C statistic cannot be computed for models fitting multiple imputation data.

goals and personal ability to successfully pursue these pathways may generate positive affect and diminish negative affect.<sup>45</sup> Adjusting for this effect, the children of parents with high scores on the hope dispositional trait scale were more likely to have subsequent LOI orders enacted. We had hypothesized this relationship reasoning that parents of children with life-threatening illnesses, if they have higher levels of hopeful patterns of thinking, would be more likely to consider a broader array of possible goals of care and potentially shift goals in light of changing clinical circumstances.<sup>9,27</sup>

This study had several limitations as well as strengths. First, from our single hospital site we enrolled only English-speaking parents who were already engaged in receiving pediatric palliative care consultative services, with further self-selection of those parents willing to participate in the study. Second, our limited sample size precludes subanalyses, such as whether the relationships observed are the same across different diseases. Third, missing data introduced the prospect of bias (which given the results of our sensitivity analysis using multiple imputation

tation we estimate to be minimal). Fourth, we cannot exclude the possibility that participation in the study was to some degree a decision-support intervention; however, only 8% of the parents in the study identified the 2 members of our study team who are also palliative care clinicians as their child's main physician. The study also has notable strengths, including the use of a prospective cohort design with validated quantitative measures and a discrete outcome in a diverse sample of pediatric palliative care patients in term of ages and conditions and an underlying basis in psychological theory and empirical findings regarding the relationships of affect and hopeful patterns of thinking to decision-making processes.

The findings of this study underscore the importance of affect and patterns of hopeful thinking in the processes of decision making when confronting serious illness and strongly suggest the need for clinicians to be aware of and respond to these influences. Specifically, clinicians can use techniques of "emotional handling" (such as asking about feelings and acknowledging and legitimizing emotions)<sup>46</sup> and further assist decision makers in exploring the variety of their hopes in a non-judgmental manner, examining the thoughts that they have about these hopes, and potentially further informing or supporting these thoughts.<sup>47</sup> Further research is warranted to test the effectiveness of these and other possible interventions and to better understand the influential role that emotions play in critical medical care decision making.

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#### Announcement

**Submissions.** The Editors welcome contributions to Picture of the Month. Submissions should describe common problems presenting uncommonly, rather than total zebras. Cases should be of interest to practicing pediatricians, highlighting problems that they are likely to at least occasionally encounter in the office or hospital setting. High-quality clinical images (in either 35-mm slide or electronic format) along with parent or patient permission to use these images must accompany the submission. The entire discussion should comprise no more than 750 words. Articles and photographs accepted for publication will bear the contributor's name. There is no charge for reproduction and printing of color illustrations. For details regarding electronic submission, please see: <http://archpedi.ama-assn.org>.