

# Investigating Parent Needs, Participation, and Psychological Distress in the Children's Hospital

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## ABSTRACT

**BACKGROUND AND OBJECTIVES:** Greater parent participation in a child's hospital care is associated with better child outcomes in the hospital and after discharge. This study examined the relationships between perceived need fulfillment for parents, parent participation in hospital care, and parent psychological distress. We hypothesized that greater perceived need fulfillment would be associated with greater participation in hospital care and decreased psychological distress.

**METHODS:** In this prospective cohort study, 166 parents completed questionnaires on a pediatric (nonintensive care) floor. Eligible parents were fluent in English and had a child who was hospitalized  $\geq 2$  nights. Previously validated questionnaires were used to assess parent participation in hospital care and psychological distress (defined here as symptoms of anxiety/depression). A modified version of the Bereaved Parent Needs Assessment was used to assess perceived need fulfillment. The association between perceived need fulfillment and each outcome variable was examined using multiple linear regression analyses.

**RESULTS:** Of 186 eligible parents, 166 were enrolled (1 declined, 19 missed/not present). In multivariable analyses, greater perceived need fulfillment was associated with greater participation in hospital care and fewer symptoms of depression, even after controlling for relevant covariates. Exploratory analyses identified needs that were differentially important within groups of parents at risk for distress.

**CONCLUSIONS:** This study suggests that assessing and supporting parent needs during a child's hospitalization may improve parent and child outcomes by increasing parents' ability to participate in hospital care and decreasing psychological distress. Future research is needed to investigate the impact of interventions targeting specific parent needs.

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Dr Jones conceptualized and designed the study, completed all aspects of data collection and data entry, conducted the initial analyses, and drafted the initial manuscript; and Drs Goldfarb, Greene, Nowacki, and Traul aided in the design of the study and reviewed and revised the manuscript. All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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The crucial role of a parent during a child's hospitalization is well established. Numerous studies have shown that parent participation in the hospital is associated with improved child hospital outcomes<sup>1-4</sup> (eg, increased comfort, improved intake and activity level, decreased length of stay), and formal interventions targeting parent participation in hospital care repeatedly demonstrate long-term benefits for the parent and the hospitalized child.<sup>4-8</sup>

Parent participation in hospital care is influenced by many factors,<sup>9</sup> including distance from the hospital, employment responsibilities, finances, and additional children at home, among others. In many cases, support from a parent's family, community, or employer can facilitate a parent's stay in the hospital; however, parents with fewer resources (or decreased access to these resources) may require additional support to enable participation in their child's care.<sup>10</sup> The goal of the present study was to examine the relationships between parent needs in the hospital, parent participation in hospital care, and parent psychological distress during a child's hospitalization on a general pediatric floor. We hypothesized that greater perceived fulfillment of parent needs during a child's admission would be associated with increased parent participation in a child's care and decreased parent psychological distress.

## METHODS

### Study Design and Measures

This study used a prospective cohort study design. Questionnaires were used to assess parent needs, need fulfillment, parent participation in hospital care, and parent psychological distress.

#### *Parent Needs and Need Fulfillment*

The Bereaved Parent Needs Assessment (BPNA)<sup>11</sup> was designed to capture a large spectrum of factors influencing parent experience, including hospital factors, family factors (eg, need for babysitting at the hospital), and community factors (eg, need for support of family and friends). Despite its original development as an instrument designed to assess the needs of bereaved parents, the large majority of

items are equally applicable to parents of children hospitalized on a general pediatric ward. The 68-item questionnaire was modified with permission of the primary author. Included were 57 of the original 68 items, with the removal of items not applicable to parents on the general pediatric floor.

Using the modified version of the BPNA, parents rated each need according to its importance and its fulfillment. Needs rated as a 4 or 5 on a 5-point Likert scale for "importance" were considered "important," and needs rated as a 4 or 5 on a 5-point Likert scale for "fulfillment" were considered "fulfilled." Parent responses to these 2 scales were used to calculate 2 unique need fulfillment scores for each parent: total need fulfillment and important need fulfillment.

Total need fulfillment was determined by calculating the fraction of total needs rated as fulfilled. For example, a parent who ranked 30 of the 57 needs as fulfilled had a total need fulfillment of  $30/57 = 0.53$  (53%). Important need fulfillment was determined by calculating the fraction of needs rated as important that were then also rated as fulfilled by a parent. For example, a parent who rated 10 needs as important and then indicated that 5 of these needs were fulfilled had an important need fulfillment of  $5/10 = 0.5$  (50%).

#### *Parent Participation*

The Index of Parent Participation<sup>12</sup> is a 36-item checklist with established reliability and validity that was developed to assess levels of parent participation in hospital care. Parents are asked to indicate all of the actions that they have performed for their child while in the hospital (eg, bathing the child). This measure has been used in previous studies<sup>7</sup> to examine the impact of interventions designed to augment parent participation, and the instrument was selected for use in this study because of its ability to be completed by parents.<sup>13</sup> In accordance with previous studies,<sup>12</sup> the number of items marked as performed for the child was summed to create a score ranging from 0 to 36, with higher scores indicating higher participation.

#### *Parent Psychological Distress*

The Hospital Anxiety and Depression Scale (HADS)<sup>14,15</sup> is a 14-item instrument that has been used extensively in the research literature to assess symptoms of anxiety and depression. Although this measure was developed for use with patients, subsequent studies have confirmed its reliability and validity in the general population.<sup>14</sup> A recent study of parents on the general pediatric wards showed that symptoms of parent psychological distress (as measured by using the HADS) were associated with posttraumatic stress symptoms in parents after discharge.<sup>16</sup> Therefore, the HADS was selected for use in the present study to evaluate parent psychological distress and risk for ongoing posttraumatic stress symptoms after discharge. To capture an appropriate time frame, parents were asked to answer each HADS item based on their current feelings.

Consistent with previous studies,<sup>14,15</sup> parent responses on each item of the HADS were scored from 0 to 3, with higher scores representing greater symptom severity. A score for parent anxiety symptoms was calculated by summing the 7 questions related to anxiety, and a score for parent depression symptoms was calculated by summing the 7 questions related to depression. Each parent's score for anxiety/depression symptoms ranged from 0 to 21, with higher scores reflecting more severe symptoms of anxiety or depression.

#### *Participants*

Participants included parents or legal guardians of children expected to be hospitalized for >2 nights who were admitted to the general pediatric floors in a major children's hospital between January and March 2016. Parents were required to be fluent in written and spoken English and were eligible for enrollment between 18 and 48 hours after their child was admitted. Parents were approached only after obtaining permission of the primary service. To minimize the study burden on families, only 1 parent was asked to participate from each family.

Parents were excluded from the study if the child was admitted for nonaccidental

trauma (suspected or confirmed), not expected to survive admission, transferred from an outside hospital where he or she had been admitted for >24 hours, or admitted from a critical care environment.

## Procedures

Eligible parents were identified by using the electronic medical record. After receiving written informed consent, the representative parent was asked to complete the questionnaires described earlier regarding their needs, the extent to which their needs had been fulfilled, their participation in hospital care, and their symptoms of psychological distress. Participants were also asked to provide basic demographic information at this time. Additional demographic information obtained from the electronic medical record included the child's age, sex, race, length of hospital stay, cause of admission, admitting service, and underlying diagnosis. If a child was transferred to an ICU, no further data were collected. Recruitment and data collection occurred between January 13, 2016, and March 15, 2016. Approval for the study was obtained from the hospital's institutional review board (number 15-1638).

## Analyses

All analyses were conducted by using JMP version 12.0 software (SAS Institute, Inc, Cary, NC). Item analysis statistics (mean, SD, number missing, and number not applicable) were computed for each of the 57 pairs of parent ratings (ie, ratings of importance and fulfillment). The original BNPA instrument does not contain a "not applicable" category. However, some parents chose to write not applicable next to specific needs. To remain consistent with previous research,<sup>11</sup> items marked as not applicable were coded as "missing." Items and cases with  $\geq 5\%$  missing values were identified and examined. After this initial assessment, the statistical software package was used to calculate the main predictor variables (ie, total need fulfillment and important need fulfillment) and outcome variables (ie, parent participation, anxiety symptoms, depression symptoms). The mean and distribution of each study variable were then assessed, and 2-tailed

bivariate correlations between all study variables were calculated.

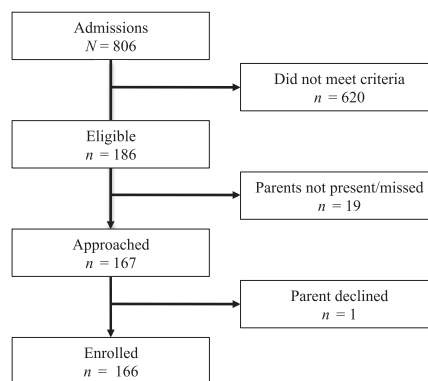
To test the study hypotheses, each of the outcome variables was regressed on each of the need fulfillment variables (ie, total need fulfillment and important need fulfillment) and relevant covariates utilizing multivariable linear regression. Additional covariates were selected empirically: any demographic or clinical variable that was simultaneously correlated ( $P < .2$ ) with 1 or more need fulfillment scores and 1 or more outcome variables was included in the regression analyses.

A sensitivity analysis was performed in which extreme outliers with respect to distance traveled (travel time >95th percentile) were removed from the data set. All conclusions remained unchanged, and thus results are not presented.

## RESULTS

### Sample

The process detailed here was used to recruit parents of children admitted to a major children's hospital between January and March 2016 (Fig 1). The most common reasons for ineligibility included length of stay <2 nights ( $n = 297$  [48%]) and



**FIGURE 1** Study enrollment. Parents were enrolled between January and March 2016. Eleven parents were not present during the majority of their child's hospitalization, and 8 parents were eligible for enrollment on a day when the study coordinator was not available. One parent declined to participate, and 166 parents were enrolled in the study.

transfer from a critical care environment ( $n = 178$  [29%]). Of the 167 parents approached to participate in the study, 166 parents (99.4%) were enrolled. Baseline demographic and clinical characteristics of the 166 enrolled parents and their children are presented in Table 1.

A total of 166 questionnaire responses were collected, and 162 parents completed all of the questionnaires. Nine individual questionnaires from 7 parents were excluded from subsequent analyses because >10% of the items were missing. Apart from these exclusions, there were few missing data, with a mean response rate of 96.8% across all questionnaire items.

### Descriptive Statistics and Correlations

Descriptive statistics for predictor and outcome variables are displayed in Table 2 along with their correlations with parent and child demographic/clinical characteristics. Several characteristics were associated ( $P < .05$ ) with 1 or more need fulfillment scores and/or outcomes. Female parent sex was related to greater total need fulfillment. Higher parent educational level and shorter travel time were related to greater important need fulfillment. Younger parent age was related to higher participation scores and higher anxiety scores. Longer travel time was related to higher depression scores. Younger child age and a greater number of previous hospital admissions were related to higher parent participation scores.

Four parent characteristics were simultaneously correlated with 1 or more need fulfillment scores and 1 or more of the outcome variables at a significance level of  $P < .2$ . These included parent age, race, educational level, and travel time to the hospital. Child age was the only child characteristic that was simultaneously correlated with 1 or more need fulfillment scores and 1 or more of the outcome variables at a significance level of  $P < .2$ . These variables were included as covariates in the multivariable analyses.

### Primary Outcomes

The results of the multiple linear regression analyses are included in Table 3. Greater total need fulfillment significantly predicted

**TABLE 1** Family, Parent, and Child Characteristics

Characteristic	Value
Parents/guardians ( <i>N</i> = 166)	
Female	131 (79)
Marital status	
Single	34 (20)
Married/engaged	113 (68)
Separated/divorced	16 (10)
Widowed/widower	1 (<1)
Not reported	2 (1)
Ethnicity/race	
White	123 (74)
African American	28 (17)
Hispanic	2 (1)
Other	13 (8)
Education	
GED/high school or less	58 (35)
Associates degree or higher	100 (60)
Not reported	8 (5)
Employment status	
Full-time	104 (63)
Part-time	25 (15)
Unemployed	34 (20)
Not reported	3 (2)
Travel time to hospital, median (range), min	35 (5–480)
Age, mean ± SD (range), y	37.4 ± 9.2 (18–60)
Children ( <i>N</i> = 166)	
Female	77 (46)
Age, mean ± SD (range), y	7.1 ± 6.3 (0.01–17)
Ethnicity/race	
White	120 (72)
African American	31 (19)
Hispanic	1 (<1)
Other	11 (7)
Information not available	3 (2)
Medical history	
Healthy	51 (31)
Underlying medical condition	115 (69)
No. of previous admissions	
None	57 (34)
1–3	66 (40)
4–10	24 (15)
>10	12 (7)
Not reported	7 (4)
Admitting service	
Hospitalist	100 (60)
Specialty service <sup>a</sup>	66 (40)
Unplanned admission	136 (82)
Length of stay, mean ± SD (range), h	83 ± 64 (34–634)

Data are presented as *n* (%), unless indicated otherwise. GED, General Educational Development test.  
<sup>a</sup> Did not include hematology/oncology or epilepsy services, which are housed in separate wings of the children's hospital.

higher parent participation scores ( $\beta = 12.12$ ;  $P = .003$ ), with lower educational level predicting lower parent participation scores ( $\beta = -1.14$ ;  $P = .037$ ) in this model. None of the variables in the model using important need fulfillment significantly predicted parent participation scores.

Younger parent age significantly predicted higher anxiety scores ( $\beta = -.12$ ;  $P = .014$ ). Neither measure of need fulfillment was associated with anxiety symptoms.

Greater total need fulfillment significantly predicted lower depression scores ( $\beta = -4.74$ ;  $P = .009$ ), as did shorter travel time to the hospital ( $\beta = .01$ ;  $P = .007$ ). Similar results were obtained when using important need fulfillment.

### Exploratory Subgroup Analyses

To identify unique patterns of needs within groups of parents most at risk for psychological distress after a child's hospitalization, parents were stratified according to known demographic risk factors, including lower educational level (58 parents), non-white race/ethnicity (43 parents), and single marital status (51 parents). For each of the 57 needs, the percentage of parents rating the need as important was compared between the high- and low-risk groups. Needs for which the percentage differed between groups by at least 15% (for importance only) are included in Table 4, and an individual need was included only if >95% of parents provided responses. As shown, certain needs were rated as more important by parents in the high-risk groups. For most needs included in Table 4, the difference between groups with respect to need fulfillment was <15%.

## DISCUSSION

### Parent Need Fulfillment and Parent Participation

The results of the present study support the hypothesis that greater perceived fulfillment of parent needs is associated with greater participation in hospital care. Specifically, multiple regression analyses showed that perceived need fulfillment was a significant predictor of parent participation, even after controlling for relevant parent factors (ie, age, education, race, travel time to the

**TABLE 2** Descriptive Statistics of Predictor/Outcome Variables and Correlations With Demographic/Clinical Variables

Variable	Total Need Fulfillment	Important Need Fulfillment	Parent Participation	Parent Anxiety	Parent Depression
Descriptive statistics					
Mean ± SD	0.89 ± 0.13	0.94 ± 0.10	23.5 ± 6.5	6.9 ± 3.7	3.5 ± 2.9
Range	0.28–1	0.37–1	5–36	0–17	0–14
Demographic/clinical variables					
Parent age (y), <i>n</i> = 164 <sup>a</sup>					
Correlation	−0.11	−0.09	−0.17	−0.19	−0.05
Significance <sup>b</sup>	0.15	0.26	0.03	0.02	0.50
Parent race (non-white), <i>n</i> = 166 <sup>a</sup>					
Slope	0.01	0.01	0.95	−0.53	0.01
Significance	0.52	0.16	0.11	0.13	0.98
Parent educational level (≤GED), <i>n</i> = 158 <sup>a</sup>					
Slope	0.02	0.02	−0.90	0.02	0.17
Significance	0.13	0.03	0.10	0.94	0.47
Travel time to hospital (min), <i>n</i> = 165 <sup>a</sup>					
Correlation	−0.08	−0.18	0.04	0.07	0.21
Significance	0.34	0.02	0.62	0.40	0.01
Parent sex (female), <i>n</i> = 166					
Slope	0.03	0.01	0.50	0.33	−0.09
Significance	0.01	0.23	0.43	0.38	0.75
Marital status (single), <i>n</i> = 164					
Slope	0.00	−0.01	0.59	−0.23	0.07
Significance	0.75	0.37	0.29	0.48	0.78
Parent employment (unemployed), <i>n</i> = 163					
Slope	0.00	0.00	−0.30	0.43	0.37
Significance	0.79	0.85	0.64	0.26	0.20
Child age (y), <i>n</i> = 166 <sup>a</sup>					
Correlation	−0.10	−0.10	−0.21	−0.10	−0.05
Significance	0.19	0.199	0.01	0.199	0.54
Child sex (female), <i>n</i> = 166					
Slope	0.01	0.01	−0.32	−0.11	0.22
Significance	0.63	0.56	0.53	0.72	0.33
Medical history (previous diagnosis), <i>n</i> = 166					
Slope	−0.01	−0.01	−0.23	0.16	0.05
Significance	0.29	0.37	0.68	0.62	0.85
No. of previous admissions, <i>n</i> = 159					
Correlation	0.02	−0.01	0.23	0.04	0.05
Significance	0.85	0.86	0.004	0.67	0.54
Admitting service (specialty service), <i>n</i> = 166					
Slope	−0.01	−0.01	0.07	−0.30	−0.24
Significance	0.30	0.51	0.90	0.33	0.31
Reason for admission (unplanned), <i>n</i> = 166					
Slope	0.02	0.01	0.42	0.41	0.31
Significance	0.10	0.41	0.52	0.28	0.29
Time since admission (h), <i>n</i> = 166					
Correlation	−0.04	0.01	0.11	−0.02	−0.08
Significance	0.65	0.91	0.16	0.80	0.34

**TABLE 2** Continued

Variable	Total Need Fulfillment	Important Need Fulfillment	Parent Participation	Parent Anxiety	Parent Depression
Length of stay (h), <i>n</i> = 166					
Correlation	-0.03	0.04	0.12	-0.10	0.08
Significance	0.72	0.64	0.14	0.23	0.29

GED, General Educational Development test.

<sup>a</sup> Variables were simultaneously correlated ( $P < .2$ ) with 1 or more predictor variables and 1 or more outcome variables and were therefore included as covariates in multiple linear regression analyses.

<sup>b</sup> All significance levels are 2-tailed.

hospital) and for relevant child factors (ie, age).

This result is consistent with previous research showing that parents who feel more prepared to interact with the hospital environment are more effective participants in their child's care.<sup>4-8</sup> For example, multiple studies have shown that providing structured information to parents about what to expect during a child's hospital stay (eg, regarding the child's appearance and accepted parental role) improves parents' capacity to participate in their child's care. The present study broadens and extends this finding, demonstrating that parents who feel that their own needs in the hospital are being met may be more equipped to participate in their child's care. Conversely, parents who are actively engaged in their child's care may feel that their needs as parents are being better met, an important consideration as our health care system moves toward quality-based metrics incorporating patient experiences.

Certain factors outside the hospital may have also contributed to the observed relationship between perceived need fulfillment and parent participation. For example, the results of our exploratory analyses support the role of logistical factors in limiting parents' ability to participate in hospital care. Single parents were more likely to endorse a need for access to child care at the hospital, suggesting that this group of parents may face additional challenges in arranging care for children at home while staying with a child in the hospital. In this context, parents whose individual needs are better met (eg, by receiving vouchers for food/parking or having access to child care at the hospital) will be better equipped to manage demands

outside of the hospital and therefore more able to participate in hospital care. This conclusion is supported by the observation that single parents were more likely to rate the need to have child care available in the hospital as fulfilled, suggesting that parents with fewer resources outside of the hospital are more likely to use hospital resources when available. These results contribute to recent research<sup>10</sup> highlighting the role of hospital accommodations in shaping family experience and ability to participate in hospital care. Together, these findings depict a complex interaction between each parent's community and their hospital-related needs, and they emphasize the importance of providing hospital resources as a means of offsetting logistical challenges faced by parents.

### Parent Need Fulfillment and Parent Psychological Distress

The results of this study support the hypothesis that greater perceived parent need fulfillment is associated with fewer symptoms of psychological distress. Specifically, multiple regression analyses showed that greater perceived need fulfillment was a significant predictor of fewer symptoms of depression, even after controlling for relevant parent and child factors. This result is consistent with previous research documenting the positive impact of hospital interventions designed to address specific parent needs (eg, information regarding a child's expected hospital course).<sup>5-8</sup> By demonstrating this relationship outside of the context of a formal intervention, the results from this study both underscore and extend this observation.

Our results also contribute nuanced information to the body of knowledge

regarding psychological distress for parents after a child's hospitalization. Although previous studies have identified factors that increase parents' risk for negative outcomes after a child's hospitalization,<sup>11,16-19</sup> the mechanisms underlying these relationships are not known. Our exploratory analyses suggest that parents within these higher risk groups may have additional needs that, if unmet, could contribute to higher levels of psychological distress. In this case, meeting parents' individual needs in the hospital could reduce disparities that are often accepted as unavoidable.

Several explanations could account for the lack of an observed relationship between need fulfillment and anxiety symptoms. For example, because this study did not incorporate a measure for pre-existing anxiety or depression, these parent characteristics may have confounded the relationship between need fulfillment and anxiety symptoms.

The conclusions of this study should be considered in light of the study's strengths and limitations. Limitations of this study include recruitment at a single children's hospital, lack of information on baseline parent coping strategies and underlying psychiatric conditions, and a brief follow-up period. In addition, the relative homogeneity of the study sample (ie, English-speaking and mostly white, with at least some college education) may limit the generalizability of study findings to other cultural/social contexts. It is worth noting that the present study did not restrict inclusion according to underlying diagnosis, reason for admission, or the admitting specialty; this approach increased the diversity of the sample and the generalizability of study conclusions



**TABLE 3** Multiple Regression Analyses

Variable	Regression Coefficient	95% Confidence Interval	P
Factors related to parent participation (n = 150)			
Total need fulfillment	12.12	4.09 to 20.15	.003
Parent age, y	−0.01	−0.18 to 0.16	.91
Parent race, non-white	0.96	−0.26 to 2.19	.12
Parent education, ≤GED	−1.14	−2.20 to −0.07	.04
Travel time to hospital, min	0.01	−0.01 to 0.03	.16
Child age, y	−0.18	−0.44 to 0.07	.16
$R^2 = 0.13, F_{6,143} = 3.71, P = .002$			
Important need fulfillment	5.53	−4.89 to 15.95	.30
Parent age, y	−0.02	−0.19 to 0.15	.81
Parent race, non-white	0.97	−0.29 to 2.24	.13
Parent education, ≤GED	−1.03	−2.13 to 0.07	.07
Travel time to hospital, min	0.01	−0.01 to 0.04	.16
Child age, y	−0.18	−0.44 to 0.08	.17
$R^2 = 0.09, F_{6,143} = 2.30, P = .038$			
Factors related to parent anxiety symptoms (n = 146)			
Total need fulfillment	−1.31	−5.90 to 3.29	.58
Parent age, y	−0.12	−0.22 to −0.03	.01
Parent race, non-white	−0.64	−1.36 to 0.08	.08
Parent education, ≤GED	0.07	−0.54 to 0.69	.81
Travel time to hospital, min	0.01	−0.01 to 0.02	.37
Child age, y	0.05	−0.10 to 0.20	.49
$R^2 = 0.08, F_{6,139} = 1.96, P = .076$			
Important need fulfillment	−2.33	−8.13 to 3.47	.43
Parent age, y	−0.12	−0.22 to −0.02	.02
Parent race, non-white	−0.62	−1.34 to 0.11	.09
Parent education, ≤GED	0.09	−0.53 to 0.71	.76
Travel time to hospital, min	0.01	−0.01 to 0.02	.41
Child age, y	0.05	−0.10 to 0.19	.51
$R^2 = 0.08, F_{6,139} = 2.01, P = .068$			
Factors related to parent depression symptoms (n = 150)			
Total need fulfillment	−4.74	−8.30 to −1.19	.009
Parent age, y	−0.03	−0.10 to 0.05	.44
Parent race, non-white	−0.05	−0.60 to 0.50	.86
Parent education, ≤GED	0.35	−0.12 to 0.82	.14
Travel time to hospital, min	0.01	0.00 to 0.02	.007
Child age, y	−0.01	−0.12 to 0.10	.86
$R^2 = 0.11, F_{6,143} = 2.84, P = .012$			
Important need fulfillment	−6.03	−10.51 to −1.54	.009
Parent age, y	−0.02	−0.10 to 0.05	.55
Parent race, non-white	0.00	−0.55 to 0.55	.99
Parent education, ≤GED	0.37	−0.10 to 0.85	.12
Travel time to hospital, min	0.01	0.00 to 0.02	.01
Child age, y	−0.02	−0.13 to 0.10	.78
$R^2 = 0.11, F_{6,143} = 2.85, P = .012$			

GED, General Educational Development test.

**TABLE 4** Exploratory Subgroup Analysis

Individual Needs	% Subgroup Rating Need as important <sup>a</sup>		% Subgroup Rating Need as Fulfilled <sup>b</sup>	
	Education ≤GED <sup>c</sup> (n = 58)	Education >GED <sup>c</sup> (n = 100)	Education ≤GED (n = 58)	Education >GED (n = 100)
To not feel blamed for my child's condition	91	72	91	95
For my culture to be respected	67	51	85	81
For my religion to be respected	68	53	83	82
To have time alone with my child	97	81	98	97
To express emotions in my own way	88	72	96	91
	Non-White Race/Ethnicity <sup>d</sup> (n = 43)		White Race/Ethnicity <sup>d</sup> (n = 123)	
To have child care (babysitting) at the hospital	42	22	56	46
To have help keeping my life going (eg. groceries, laundry, mail)	65	41	69	48
For my culture to be respected	86	47	90	79
For my religion to be respected	86	50	92	77
To express emotions in my own way	93	73	93	93
For hospital staff to acknowledge my pain	79	63	90	87
	Unpartnered <sup>e</sup> (n = 51)		Partnered <sup>e</sup> (n = 113)	
To have child care (babysitting) at the hospital	41	21	58	43
To have help keeping my life going (eg. groceries, laundry, mail)	57	42	70	46

Needs were included in the table if >95% of both subgroups provided data regarding the need's importance and if the difference in percentages between subgroups was  $\geq 15\%$ . GED, General Educational Development test.

<sup>a</sup> Rated as 4 or 5 on a 5-point Likert scale for importance.

<sup>b</sup> Rated as 4 or 5 on a 5-point Likert scale for fulfillment.

<sup>c</sup> Included some grade school, GED/high school, and some college.

<sup>d</sup> Included associates or vocational degree, 4-year college degree, master's degree, and professional doctorate degree.

<sup>e</sup> Included African American, Hispanic, and other.

<sup>f</sup> Included white.

<sup>g</sup> Included single, separated/divorced, and widowed/widower.

<sup>h</sup> Included married/engaged.



among parents of children admitted to the general pediatric floor. In addition, although the short time available for follow-up with parents precluded assessment of long-term outcomes (eg, posttraumatic stress symptoms), this study was designed to examine psychological distress, which has been shown in earlier studies to significantly predict posttraumatic stress symptoms after discharge.<sup>16,20–22</sup>

Major strengths of the present study include its large sample size, high rate of participation, lack of missing data, and prospective design. The sample size exceeds the numbers obtained by most previous studies of parents in the children's hospital,<sup>7,11,16</sup> including several multisite studies. This relatively large sample size permitted statistical adjustment for multiple parent and child variables during data analysis. Another major strength of this study is the high response rate from parents who were asked to participate, which significantly limited/eliminated the impact of voluntary response bias and nonresponse bias.

## CONCLUSIONS

This study emphasizes the importance of identifying and addressing parents' individual needs in the course of a child's hospitalization. Supporting parents in this way may improve parent and child outcomes by increasing parents' ability to participate in hospital care and by decreasing parent psychological distress. Additional research is needed to clarify the role of specific parent needs at different points after a child's hospitalization and to rigorously investigate the needs of underrepresented groups of parents (eg, fathers, non-English-speaking parents, non-white parents). Future investigations may also examine the relationship between need fulfillment and child outcomes to determine if the observed association between need fulfillment and parent participation is associated with a clinically meaningful impact on the hospitalized child.

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