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## The Bereaved Parent Needs Assessment: A new instrument to assess the needs of parents whose children died in the pediatric intensive care unit\*

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### Abstract

**Objectives**—To evaluate the reliability and validity of the Bereaved Parent Needs Assessment, a new instrument to measure parents' needs and need fulfillment around the time of their child's death in the pediatric intensive care unit. We hypothesized that need fulfillment would be negatively related to complicated grief and positively related to quality of life during bereavement.

**Design**—Cross-sectional survey.

**Setting**—Five U.S. children's hospital pediatric intensive care units.

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\*See also p. 3103.

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**Subjects**—Parents (n = 121) bereaved in a pediatric intensive care unit 6 months earlier.

**Interventions**—Surveys included the 68-item Bereaved Parent Needs Assessment, the Inventory of Complicated Grief, and the abbreviated version of the World Health Organization Quality of Life questionnaire. Each Bereaved Parent Needs Assessment item described a potential need and was rated on two scales: 1) a 5-point rating of importance (1 = not at all important, 5 = very important) and 2) a 5-point rating of fulfillment (1 = not at all met, 5 = completely met). Three composite scales were computed: 1) total importance (percentage of all needs rated 4 or 5 for importance), 2) total fulfillment (percentage of all needs rated 4 or 5 for fulfillment), and 3) percent fulfillment (percentage of important needs that were fulfilled). Internal consistency reliability was assessed by Cronbach's  $\alpha$  and Spearman-Brown-corrected split-half reliability. Generalized estimating equations were used to test predictions between composite scales and the Inventory of Complicated Grief and World Health Organization Quality of Life questionnaire.

**Measurements and Main Results**—Two items had mean importance ratings  $<3$ , and 55 had mean ratings  $>4$ . Reliability of composite scores ranged from 0.92 to 0.94. Total fulfillment was negatively correlated with Inventory of Complicated Grief ( $r = -.29$ ;  $p < .01$ ) and positively correlated with World Health Organization Quality of Life questionnaire ( $r = .21$ ;  $p < .05$ ). Percent fulfillment was also significantly correlated with both outcomes. Adjusting for parent's age, education, and loss of an only child, percent fulfillment remained significantly correlated with Inventory of Complicated Grief but not with World Health Organization Quality of Life questionnaire.

**Conclusions**—The Bereaved Parent Needs Assessment demonstrated reliability and validity to assess the needs of parents bereaved in the pediatric intensive care unit. Meeting parents' needs around the time of their child's death may promote adjustment to loss. (*Crit Care Med* 2012; 40:3050–3057)

### Keywords

bereavement; death; grief; intensive care; parents; pediatrics; quality of life

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The death of a child is an overwhelming experience for most parents (1, 2). Many personal and interpersonal needs arise that are often shaped by the setting and circumstances in which the child's death occurred. For example, the needs of parents bereaved in pediatric intensive care units (PICUs) are often related to the highly technological environment, the multitude and diversity of staff, and the rapid pace of complex decision making (3). Parents bereaved in PICUs are at high risk for complicated grief, a condition characterized by intense and prolonged symptoms that interfere with daily functioning (4–6). Health professionals working in PICUs must seek to understand parents' needs to provide appropriate supportive care and promote adjustment to loss.

Most prior studies evaluating the needs of parents bereaved in PICUs have used qualitative methods such as interviews and focus groups (3, 7–12). Findings from these studies provide insight into parents' perspectives of their needs based on their lived experiences. Some identified needs include maintaining the parent-child relationship; honest communication; kindness and compassion from PICU staff; privacy, enough time, and a reverent atmosphere near the time of death; support from family and friends; follow-up care; and finding meaning in the experience (3, 7–12). However, most of these qualitative studies have been conducted at single centers with relatively small samples potentially limiting their generalizability. A quantitative instrument would enable broader evaluation of bereaved parents' needs across multiple PICU settings; however, no validated instruments were found that are specific for this purpose (13).

The objective of this study is to evaluate the reliability and validity of the Bereaved Parent Needs Assessment (BPNA), a new instrument to measure parents' needs around the time of their child's death in the PICU and the extent to which parents perceive their needs as met. The items of this new tool were developed by an interdisciplinary team of investigators based on prior qualitative research and the input of content experts (3, 7, 8, 14). We hypothesized that fulfillment of parents' needs around the time of their child's death would be negatively related to the extent of complicated grief symptoms and positively related to quality of life during bereavement.

## Methods

### BPNA Instrument Development

Details of generating item content, formatting, ordering, and using content experts to guide instrument development have been reported elsewhere (14). Extensive qualitative research consisting of individual interviews and focus groups with bereaved parents and hospital chaplains who work with bereaved parents was conducted over a 6-yr period to gain a better understanding of bereaved parents' needs (3, 7, 8). Interview and focus group questions were designed to elicit parents' and chaplains' perceptions of parents' informational, emotional, social, physical/environmental, and spiritual needs around the time of their child's death in the PICU. From this qualitative work, we generated a detailed listing of categories pertaining to parents' needs. Based on this detailed listing, we drafted an initial pool of items representing specific needs within each category. As items were generated, we regularly returned to the original interview and focus group transcripts to review parents' descriptions of their needs. Each item was discussed extensively by our interdisciplinary team with several items being modified, combined, or eliminated resulting in an intermediate pool of 101 items. A two-part item response format was selected based on the work of Kristjánssdóttir (15) and Shields et al (16). Respondents were instructed to think back to the time around their child's death, and first, rate the importance of each need item on a 5-point scale (1 = not at all important, 5 = very important), and second, rate the extent to which each need item was fulfilled (1 = not at all met, 5 = completely met). Only the end points were labeled, and the middle number, 3, was clearly centered between the labeled end points. Next, content experts including health researchers, experienced clinicians, and bereaved parents evaluated the relevance and clarity of each item, identified redundant items for elimination, and provided comments on specific items and the overall format of the instrument. Based on this feedback, the total number of items was reduced to 68 in the current BPNA version (Supplemental Digital Content 1, <http://links.lww.com/CCM/A485>).

### BPNA Psychometric Testing

**Design and Setting**—A cross-sectional survey was conducted across five U.S. children's hospital PICUs to assess the validity and reliability of the 68-item BPNA. The study was approved by the institutional review board at each site.

**Eligibility**—Biological parents and legal guardians (collectively referred to hereafter as parents) of children who died in a participating PICU between June 1, 2009, and May 31, 2011, were eligible. Medical records of the deceased children were reviewed to obtain the parents' contact information and primary language. Parents who did not speak English were excluded.

**Data Collection**—Eligible parents were mailed survey booklets 6 months after their child's death. If completed surveys were not returned within 1 month, telephone contact was attempted to offer parents the option of completing the survey by telephone. Survey booklets included sections on parent demographics and child clinical characteristics, the 68-item

BPNA, the Inventory of Complicated Grief (ICG) (17), the abbreviated version of the World Health Organization Quality of Life questionnaire (WHOQOL-BREF) (18), and two items on the degree of difficulty and time spent completing the survey booklet. Parent demographics included age, sex, race, ethnicity, marital status, education, relationship to the deceased child, and number of living children. Relationship to the deceased child was categorized as biological or other legal guardian. Child clinical characteristics included age, sex, cause of death, total number of hospital and PICU admissions, and the duration of the last PICU stay. Cause of death was categorized as cardiac, respiratory, malignancy, sepsis/multiple organ failure, neurologic, trauma, or others.

The ICG is a 19-item measure of the severity of complicated grief symptoms (17). Respondents report the frequency with which they currently experience the cognitive, emotional, or behavioral state described in each item. Responses are rated on a 5-point scale (0 = never, 4 = always). Item responses are summed to obtain total scores ranging from 0 to 76. Higher scores indicate more symptoms. ICG scores >25 have been associated with impaired general, mental, and physical health, poor social functioning, and bodily pain (17). Scores  $\geq 30$  at least 6 months after a death have been used to indicate complicated grief (4, 5, 19). Therefore, we used a time point of 6-month postdeath to survey parents.

The WHOQOL-BREF is a 26-item scale that covers four broad domains of quality of life, including physical health, psychological health, social relationships, and environment (18). Respondents rate each item on a 5-point scale reflecting how much, how completely, how often, how good, or how satisfied they felt about the content described in the item during the past 4 wks. Scores are transformed to a scale of 1–100. Higher scores indicate greater quality of life.

### statistical analysis

Item analysis statistics (mean, SD, item-to-total correlations, number missing, and number nonapplicable [NA]) were computed for each of the 68 pairs of BPNA scales (i.e., importance rating and fulfillment rating). While there was no NA category, when respondents wrote in “NA” these were coded separately and later combined and treated as one missing value category. Items and cases with  $\geq 5\%$  missing were identified and examined. Multiple regression was used to impute missing and NA item responses. Importance items were regressed on importance scales and fulfillment items were regressed on fulfillment scales. Random error was added to imputed values, and estimates were rounded to the nearest integer (1–5) to maintain consistency in the response format.

To score the BPNA, a total score was computed for each response type (i.e., importance rating and fulfillment rating) by summing the number of items with a 4 or 5 rating, dividing by 68, and multiplying by 100. This produced total importance and total fulfillment scores. One additional BPNA scale, percent fulfillment, was computed to reflect the percent of important needs that were fulfilled. It was computed by adding up all items that were rated as both important (rated 4 or 5) and fulfilled (rated 4 or 5), dividing this sum by the number of items rated as important, and multiplying by 100.

Internal consistency reliability was assessed by Cronbach's  $\alpha$  for the total importance and total fulfillment scales. Reliability of the percent fulfillment scale was assessed using the Spearman-Brown–corrected split-half reliability coefficient because different sets of items were summated for different respondents depending on perceptions of importance. Principal components item analysis was performed on each scale to determine the dominance of the first component.

Criterion-related validity of the BPNA scales was investigated using generalized estimating equations. We hypothesized that percent fulfillment would be negatively related to ICG and positively related to WHOQOL-BREF scores. We also hypothesized that the correlations with ICG would be stronger than with WHOQOL-BREF due to the more specific problems in adjustment addressed by the ICG. In separate analyses, ICG and WHOQOL-BREF were regressed on each of the BPNA scales and other covariates. The other covariates were selected empirically; any of the demographic or clinical variables that were simultaneously correlated ( $p < .1$ ) with a BPNA scale and WHOQOL-BREF or ICG was included in the regression. To aid interpretation and comparison across scales, the BPNA scales, WHOQOL-BREF and ICG were standardized (mean = 0,  $SD = 1$ ) prior to analysis. With standardization, the regression coefficients are interpreted as semipartial correlation coefficients. Generalized estimating equation was used for the analysis to take into account the statistical dependence among parents of the same child (e.g., spouses). Because the outcomes were continuous, a normal link function was used in the generalized estimating equation regressions. All analyses were conducted using IBM SPSS version 20.0 (SPSS, Chicago, IL).

## Results

During the study period, 437 families were eligible to participate. One or both parents from 94 (22%) families responded to the survey. Among nonrespondents, we were unable to reliably differentiate families who refused to participate from those unable to be contacted because nondeliverable surveys were inconsistently returned and telephone answering machine messages often failed to identify the phone's owner. A total of 122 survey responses were collected; 114 by mail and eight by telephone. One survey was excluded from all analyses because 51 of the 68 BPNA fulfillment ratings were missing. Otherwise, there were very little missing data with a mean response rate across all survey items of 97.4%. Average rate of missing (including NA) responses across the BPNA items was 2.2% and 5.1% for importance and fulfillment items, respectively. The final data set consisted of 121 surveys from parents of 94 children. Of these, 13 (11%) reported the survey was "very easy" to complete, 31 (26%) "easy," 47 (39%) "neither easy nor hard," 20 (16%) "hard," six (5%) "very hard," and four (3%) did not rate the degree of difficulty. Ninety-nine (82%) reported completing the survey booklet in <1 hr. Parent demographics and child clinical characteristics are presented in Table 1. Only one child died from nonaccidental trauma (i.e., shaken baby syndrome).

Item statistics for BPNA importance scales are shown in Table 2. As expected, importance was rated high for most needs. In all, 55 of 68 (81%) importance items had a mean rating of 4. Items were rank ordered by mean from high to low importance and there was no obvious discontinuity marking more or less important items. Only two items had a mean importance rating of <3, "to blame someone for my child's death," and "to have childcare (babysitting) at the hospital." These importance ratings support the content validity of the items because only items expected to be important were included

Item statistics for BPNA fulfillment scales are also shown in Table 2. These items elicited a greater range of responses although 56 of 68 (82%) items had a mean rating of 4.0, indicating that needs were met well or completely met. Items were rank ordered to identify needs that received the lowest fulfillment ratings. Of these, six received importance ratings of 4 (items 29, 32, 35, 62, 67, and 68) and six received importance ratings <4 (items 31, 33, 57, 61, 65, and 66). Items in the first group could be considered important needs not well met. These include "to have a place to sleep in the hospital," "to be able to sleep in my child's room," "to be told that my child was likely to die," "to understand the medical cause of my child's death," "to find meaning in my loss," and "to have hope for the future."

Item-total correlations were positive for all items on each scale. There was no indication in the item statistics that any items should be removed from the total scale scores. The first principal component of each scale was clearly dominant. For importance items, the first principal component accounted for 24% of the variance among the items compared to 9% and 5% for the next most dominant components. Fifteen importance items had loadings  $>0.6$  on the first component and only one importance item had a loading  $>0.6$  on the second component. For fulfillment items, the first principal component accounted for 26% of the variance among the items compared to 6.2% and 5.6% for the next most dominant components. Eighteen fulfillment items had loadings  $>0.6$  on the first component and none had loadings this large on the second component. These results clearly indicate the presence of unitary underlying factors.

BPNA scale statistics, correlations, and reliabilities are shown in Table 3. For the total importance scale, the mean score was 86.95%, suggesting that the BPNA items reflect needs perceived as important by parents. For the total fulfillment scale, the mean score was 80.74%, indicating a high level of fulfillment across all needs in this sample. For the percent fulfillment scale, the mean score was 83.73%, indicating a high level of fulfillment of important needs. Total importance was moderately correlated with total fulfillment. Total fulfillment was highly correlated with percent fulfillment. Each of the BPNA scales had high reliability ( $>0.90$ ).

Correlations of parent demographics and child clinical characteristics with the BPNA scales and outcomes are shown in Table 4. Several demographic and clinical variables were related ( $p < .05$ ) to one or more BPNA scales. Parent gender, loss of an only child, and child age were related to total importance scores. Parent age, gender, ethnicity, education, and loss of an only child were related to total fulfillment. Parent age, gender, education, and loss of an only child were related to percent fulfillment. Several demographic and clinical variables were related ( $p < .05$ ) to one or more outcomes. Death due to trauma, shorter PICU length of stay, lower education level, and being the biological parent were all related to higher ICG scores. Lower education was also related to lower WHOQOL-BREF scores.

Three of these demographic and clinical variables were simultaneously correlated with one or more BPNA scales and one of the outcomes, either ICG or WHOQOL-BREF at a significance level of  $p < .1$ . These included parent's age, loss of an only child, and level of education. These variables were used as covariates in the multivariable analysis.

Correlations and adjusted correlations of the BPNA scales with ICG and WHOQOL-BREF are shown in Table 5. ICG scores were  $31.4 \pm 14.3$  and WHO-QOL-BREF scores were  $63.4 \pm 16.3$ . Total importance was not correlated with ICG or WHOQOL-BREF. As expected, total fulfillment was negatively correlated with ICG ( $r = -.29$ ;  $p < .01$ ) and positively correlated with WHOQOL-BREF ( $r = .21$ ;  $p < .05$ ). Percent fulfillment was also significantly correlated with both outcomes. Adjusting for parent's age, education level, and loss of an only child, percent fulfillment remained significantly correlated with ICG but not with WHOQOL-BREF scores.

## Discussion

In this report, we describe the BPNA, a new instrument designed to measure parents' needs around the time of their child's death in the PICU and the extent to which parents perceive their needs as met. Total importance and total fulfillment scores were high (means  $>80\%$ ), suggesting that the BPNA items reflect parents' perceptions of their needs and that most of these needs were well or completely met. Several important unmet needs were also

identified and a scale, percent fulfillment, was derived to reflect the extent to which important needs were met or unmet. Each BPNA scale demonstrated high reliability.

As expected, parents who perceived greater need fulfillment experienced less complicated grief symptoms during bereavement as measured by the ICG and better quality of life as measured by the WHOQOL-BREF. Also as expected, the relationship between need fulfillment and complicated grief symptoms was stronger than that between need fulfillment and quality of life likely due to the more specific nature of the ICG for bereavement-related problems. When adjusted for parent's age, education level, and the loss of an only child, the percent of important needs fulfilled remained significantly related to the extent of complicated grief symptoms but not quality of life. Together, these findings support the validity and reliability of the BPNA as a tool to measure bereaved parents' needs and need fulfillment.

Complicated grief is a chronic debilitating condition characterized by intense yearning for the deceased, frequent thoughts and images of the deceased, feelings of shock and disbelief, extreme loneliness and lack of purpose, and avoidance of reminders of the deceased or excessive proximity seeking (6). Symptoms are persistent and lead to impaired occupational, social, and relational functioning. Parents in our study reported high levels of complicated grief symptoms (ICG  $31.4 \pm 14.3$ ) 6 months after their child's death consistent with reports from other samples of parents bereaved in PICUs (4, 5). Demographic and clinical variables observed in our study to be associated with complicated grief symptoms such as death due to trauma, shorter PICU length of stay, lower parent education, and being the biological parent are also consistent with prior research findings (4, 5, 20–25). The inverse relationship between percent fulfillment and ICG scores suggests that failure to meet parents' needs around the time of their child's death may put parents at greater risk for developing complicated grief. The relationship between percent fulfillment and ICG was not strong (adjusted  $r = -.21$ ), possibly due to the many other factors potentially contributing to the development of complicated grief. However, health professionals should still carefully consider parents' needs around the time of a child's death because, unlike other unalterable risk factors, many parent needs can be met through high-quality interactions with health professionals.

Findings from our study elucidate important parental needs that are often not well met in PICUs. Some of these important unmet needs are likely related to deficiencies in the physical environment or operational policies of some hospitals regarding their ability to support family-centered care (e.g., place for parents to sleep in the hospital or PICU). Other important unmet needs are likely related to barriers in communication between health professionals and parents (e.g., to be told my child was likely to die and to understand the medical cause of death). Others are likely related to parents' need to make meaning of their experiences (e.g., to find meaning in the loss and hope for the future). Meaning making after a highly stressful event is believed to be a fundamental process for many individuals that when successful may lead to better adjustment (26). Our findings also demonstrate some less important unmet needs. Some of these may represent needs perceived by parents to be better met by family or friends (e.g., babysitting and help keeping life going) or negative emotions (e.g., to feel anger and to blame).

Limitations of this study include the modest percentage of families (22%) who responded to the survey. Our response rate is typical of research with bereaved parents and may reflect the added burden research participation imposes during bereavement as well as the difficulty locating parents many months after their child's death in the hospital (4, 5). The large number of females and Caucasians among respondents may also limit generalizability. No information is available regarding nonrespondents because parents' demographics and their

child's clinical characteristics were obtained by self-report. The participant to variable (PTV) ratio of parents to BPNA items in this study was smaller than the 5 to 10 sometimes recommended (27); the PTV ratio was 1.78 (121/68). However, PTV ratio rules have not been supported in methodological research (28–30) and reproducibility of results is more a function of how well components are defined by item covariances. When components are determined by 4 loadings >0.6, the PTV ratio has been considered irrelevant (29). The primary component for importance items in this study had 15 loadings >0.6 and the primary component for fulfillment items had 18. In a simulation study by Arrindell and van der Ende (28), factor structures were reliably recovered with a PTV ratio of 1.3 and a sample size of 100; therefore, we are confident our results will hold up.

Our study is also limited by its cross-sectional design. The BPNA instructs parents to think back to the time around their child's death (i.e., at least 6 months ago in this study) and respond to each item accordingly, whereas the ICG and WHOQOL-BREF instruct parents to consider how they felt about each item more recently. However, because parents completed all these measures at the same time, causal relationships cannot be inferred. For example, it is possible that parents who are experiencing complicated grief recall their PICU experiences more negatively than those who are having less difficulty adjusting. Sensitivity of the BPNA to change could not be determined because the instrument was administered only once. In addition, the BPNA cannot decipher which needs, when fulfilled, contribute most to reducing grief.

The high scores obtained on the BPNA scales in this study could represent a ceiling effect of the instrument. High scores indicate a high level of functioning with regard to meeting bereaved parents' needs and might be expected at the participating PICUs where site investigators have special research interest in providing supportive care to bereaved parents. Still, some deficiencies and areas for improvement were identified. Lower scores might be obtained in other PICU settings with less emphasis on bereavement care. The high scores on the total fulfillment and percent fulfillment scales also resulted in restricted ranges of these scales, which consequently could have artificially reduced the correlations between these scales and the ICG and WHOQOL-BREF.

We anticipate that the BPNA will best be used to assess parents' needs and fulfillment of needs within and across PICUs rather than to assess needs and fulfillment for individual parents. Using the BPNA in this way could advance both clinical practice and bereavement theory. Regarding clinical practice, PICU staff can administer the BPNA to assess how well parents' needs are being met in their unit and adjust their practice and policies accordingly. Regarding bereavement theory, the BPNA can be used to study relationships between need fulfillment in the PICU and short- and long-term outcomes for parents. New knowledge could be gained regarding the extent to which supporting parents' needs in the PICU affects various aspects of their grief trajectories.

## Conclusions

Our findings demonstrate excellent reliability and fair validity of the BPNA as a tool to measure the needs of parents bereaved in the PICU and the extent to which parents perceive their needs as met. Our findings also suggest that meeting parents' needs around the time of their child's death may influence their adjustment to loss. The BPNA can be used to identify specific areas of parental need for which supportive intervention may be needed (e.g., items with mean fulfillment scores <4) within individual PICUs or across PICUs. Further research should develop interventions to meet bereaved parents' needs and evaluate their effects on parents' adjustment.



## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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**Table 1**  
**Parent demographics and child clinical characteristics**

| <b>Parent characteristics (n = 121)</b>                                  |                 |
|--|-----------------|
| Gender, n (%)  |                 |
| Male   | 32 (26)         |
| Female   | 89 (74)         |
| Race, n (%)  |                 |
| White  | 86 (71)         |
| Black  | 22 (18)         |
| Other  | 13 (11)         |
| Ethnicity, n (%)   |                 |
| Hispanic   | 7 (6)           |
| Non-Hispanic   | 114 (94)        |
| Marital status, n (%)  |                 |
| Married  | 86 (71)         |
| Not married  | 35 (29)         |
| Age, yrs, mean $\pm$ SD  | 38.5 $\pm$ 10.5 |
| Education, yrs, mean $\pm$ SD  | 14.6 $\pm$ 2.7  |
| Relationship to child, n (%)   |                 |
| Biological parent  | 105 (87)        |
| Other legal guardian   | 15 (12)         |
| Unknown  | 1 (1)           |
| Number of living children, n (%)   |                 |
| None   | 34 (28)         |
| One  | 35 (29)         |
| Two or more  | 52 (43)         |
| Child characteristics (n = 94)   |                 |
| Gender, n (%)  |                 |
| Male   | 54 (57)         |
| Female   | 40 (43)         |
| Age, yrs, mean $\pm$ SD  | 6.5 $\pm$ 7.0   |
| Total number of hospital admissions, mean $\pm$ SD                       | 2.2 $\pm$ 0.9   |
| Total number of pediatric intensive care unit admissions, mean $\pm$ SD  | 1.8 $\pm$ 0.8   |
| Duration of last pediatric intensive care unit stay, days, mean $\pm$ SD | 2.2 $\pm$ 0.8   |
| Cause of death, n (%)  |                 |
| Sepsis/multiple organ failure  | 19 (20)         |
| Cardiac  | 15 (16)         |
| Neurologic   | 15 (16)         |
| Respiratory  | 13 (14)         |
| Malignancy   | 8 (9)           |
| Trauma   | 4 (4)           |
| Other/unknown  | 20 (21)         |

**Table 2**  
**Item statistics (n = 121)**

| Needs <sup>a</sup>  | Importance  |                                  | Fulfillment |                                  |
|---|-------------|----------------------------------|-------------|----------------------------------|
|   | Mean ± SD   | Corrected Item-Total Correlation | Mean ± SD   | Corrected Item-Total Correlation |
| 1. To participate in my child's care                                | 4.87 ± 0.53 | .331                             | 4.31 ± 0.91 | .598                             |
| 2. To make decisions for my child                                   | 4.88 ± 0.37 | .475                             | 4.36 ± 0.91 | .537                             |
| 3. To be with my child whenever I want                              | 4.93 ± 0.30 | .350                             | 4.61 ± 0.74 | .491                             |
| 4. To talk to my child  | 4.88 ± 0.41 | .391                             | 4.70 ± 0.73 | .296                             |
| 5. To touch my child  | 4.95 ± 0.28 | .386                             | 4.74 ± 0.65 | .430                             |
| 6. To hold my child   | 4.83 ± 0.55 | .259                             | 4.12 ± 1.26 | .293                             |
| 7. To protect my child  | 4.92 ± 0.43 | .356                             | 4.15 ± 1.22 | .583                             |
| 8. To have confidence in the professionals caring for my child      | 4.97 ± 0.18 | .235                             | 4.31 ± 0.96 | .659                             |
| 9. To know that my child got the best possible care                 | 4.98 ± 0.12 | .300                             | 4.30 ± 1.06 | .577                             |
| 10. To know my child's pain was adequately treated                  | 4.94 ± 0.26 | .083                             | 4.31 ± 0.98 | .472                             |
| 11. For my child's doctor to be available to me                     | 4.88 ± 0.39 | .340                             | 4.13 ± 0.98 | .673                             |
| 12. To get complete information about my child                      | 4.93 ± 0.28 | .407                             | 4.11 ± 1.11 | .611                             |
| 13. For my child's nurse to be available to me                      | 4.93 ± 0.25 | .388                             | 4.66 ± 0.67 | .532                             |
| 14. To feel free to ask questions                                   | 4.86 ± 0.41 | .416                             | 4.56 ± 0.75 | .520                             |
| 15. To have things explained in words that I can understand         | 4.86 ± 0.45 | .354                             | 4.39 ± 0.84 | .552                             |
| 16. For hospital staff to speak honestly to me                      | 4.93 ± 0.30 | .368                             | 4.23 ± 0.95 | .659                             |
| 17. For guidance from hospital staff about what to expect           | 4.85 ± 0.44 | .452                             | 4.10 ± 1.05 | .659                             |
| 18. To have hospital staff available to me                          | 4.79 ± 0.52 | .485                             | 4.53 ± 0.68 | .680                             |
| 19. To understand the roles of different people caring for my child | 4.69 ± 0.63 | .535                             | 4.38 ± 0.81 | .589                             |
| 20. To have hospital staff work as a team                           | 4.85 ± 0.42 | .548                             | 4.51 ± 0.86 | .552                             |
| 21. For my authority as a parent to be respected                    | 4.82 ± 0.53 | .563                             | 4.48 ± 0.90 | .637                             |
| 22. To not feel blamed for my child's condition                     | 4.46 ± 1.10 | .549                             | 4.46 ± 1.03 | .495                             |
| 23. To feel welcome in the pediatric intensive care unit            | 4.79 ± 0.51 | .516                             | 4.60 ± 0.78 | .614                             |
| 24. To have enough space for my family                              | 4.69 ± 0.65 | .560                             | 4.12 ± 1.06 | .434                             |
| 25. For the hospital to be clean                                    | 4.90 ± 0.32 | .417                             | 4.53 ± 0.83 | .293                             |
| 26. To feel safe in the hospital                                    | 4.81 ± 0.45 | .498                             | 4.74 ± 0.63 | .361                             |
| 27. To have food available close by                                 | 3.98 ± 1.31 | .311                             | 4.37 ± 0.84 | .258                             |

| Needs <sup>a</sup>   | Importance  |                                  | Fulfillment |                                  |
|--|-------------|----------------------------------|-------------|----------------------------------|
|  | Mean ± SD   | Corrected Item-Total Correlation | Mean ± SD   | Corrected Item-Total Correlation |
| 28. To be able to take care of my personal needs (e.g., showering, changing clothes, brushing teeth) | 3.94 ± 1.28 | .303                             | 4.14 ± 1.23 | .334                             |
| 29. To have a place to sleep in the hospital   | 4.40 ± 1.10 | .292                             | 3.97 ± 1.23 | .307                             |
| 30. To have a chapel available   | 3.69 ± 1.49 | .441                             | 4.48 ± 0.99 | .313                             |
| 31. To have childcare (babysitting) at the hospital  | 2.35 ± 1.60 | .404                             | 3.16 ± 1.54 | .259                             |
| 32. To be able to sleep in my child's room   | 4.59 ± 1.04 | .322                             | 3.67 ± 1.54 | .472                             |
| 33. To have help keeping my life going (e.g., groceries, laundry, mail)                              | 3.16 ± 1.72 | .391                             | 3.17 ± 1.54 | .362                             |
| 34. To have enough time to make decisions  | 4.70 ± 0.62 | .399                             | 4.05 ± 1.10 | .462                             |
| 35. To be told that my child was likely to die   | 4.64 ± 0.80 | .222                             | 3.92 ± 1.33 | .360                             |
| 36. To have family and friends with me at the hospital   | 4.74 ± 0.54 | .468                             | 4.64 ± 0.80 | .396                             |
| 37. To be supported by my family and friends   | 4.83 ± 0.44 | .563                             | 4.68 ± 0.73 | .542                             |
| 38. To have others understand my pain  | 4.21 ± 1.25 | .413                             | 4.02 ± 1.16 | .623                             |
| 39. To be treated with compassion by hospital staff  | 4.71 ± 0.67 | .588                             | 4.60 ± 0.81 | .620                             |
| 40. To talk to a chaplain  | 3.64 ± 1.56 | .466                             | 4.54 ± 1.02 | .302                             |
| 41. To not feel judged by hospital staff   | 4.20 ± 1.35 | .515                             | 4.45 ± 1.07 | .473                             |
| 42. For my culture to be respected   | 3.36 ± 1.76 | .609                             | 4.56 ± 0.98 | .241                             |
| 43. For my religion to be respected  | 3.91 ± 1.57 | .544                             | 4.66 ± 0.90 | .305                             |
| 44. For my child to be treated with dignity  | 4.95 ± 0.25 | .464                             | 4.68 ± 0.73 | .563                             |
| 45. To have privacy  | 4.62 ± 0.74 | .403                             | 4.47 ± 0.94 | .465                             |
| 46. To have time alone with my child   | 4.82 ± 0.46 | .449                             | 4.55 ± 0.91 | .436                             |
| 47. To say goodbye to my child   | 4.95 ± 0.28 | .446                             | 4.65 ± 0.87 | .445                             |
| 48. For my child to be called by name  | 4.74 ± 0.73 | .568                             | 4.85 ± 0.52 | .414                             |
| 49. To be there when my child died   | 4.93 ± 0.42 | .357                             | 4.74 ± 0.82 | .357                             |
| 50. For hospital staff to be respectful at the time of my child's death                              | 4.89 ± 0.48 | .462                             | 4.80 ± 0.55 | .505                             |
| 51. For my child's death to be treated as a sacred time  | 4.87 ± 0.51 | .346                             | 4.73 ± 0.65 | .459                             |
| 52. To not feel rushed when my child died  | 4.88 ± 0.51 | .465                             | 4.49 ± 1.02 | .366                             |
| 53. To have enough time to gather family   | 4.79 ± 0.66 | .306                             | 4.64 ± 0.88 | .384                             |
| 54. To have a keepsake of my child   | 4.81 ± 0.59 | .224                             | 4.73 ± 0.84 | .249                             |

| Needs <sup>a</sup>   | Importance  |                                  | Fulfillment |                                  |
|--|-------------|----------------------------------|-------------|----------------------------------|
|  | Mean ± SD   | Corrected Item-Total Correlation | Mean ± SD   | Corrected Item-Total Correlation |
| 55. To express emotions in my own way                      | 4.58 ± 0.96 | .612                             | 4.68 ± 0.73 | .422                             |
| 56. For hospital staff to acknowledge my loss              | 4.37 ± 1.08 | .649                             | 4.64 ± 0.74 | .581                             |
| 57. To have contact with hospital staff after I leave      | 3.70 ± 1.43 | .356                             | 3.80 ± 1.33 | .378                             |
| 58. To give feedback about my hospital experiences         | 3.87 ± 1.37 | .533                             | 4.04 ± 1.24 | .434                             |
| 59. To talk about my child                                 | 4.74 ± 0.75 | .395                             | 4.29 ± 1.17 | .500                             |
| 60. To remember my child in family traditions and holidays | 4.71 ± 0.75 | .459                             | 4.23 ± 1.07 | .448                             |
| 61. To talk to other parents whose children died           | 3.73 ± 1.39 | .451                             | 3.36 ± 1.51 | .315                             |
| 62. To understand the medical cause of my child's death    | 4.74 ± 0.72 | .295                             | 3.55 ± 1.51 | .398                             |
| 63. To feel that my child's life had meaning               | 4.88 ± 0.39 | .479                             | 4.30 ± 1.16 | .572                             |
| 64. To feel grateful for my child's life                   | 4.92 ± 0.35 | .376                             | 4.48 ± 0.97 | .489                             |
| 65. To feel angry about my child's death                   | 3.74 ± 1.46 | .317                             | 3.92 ± 1.21 | .344                             |
| 66. To blame someone for my child's death                  | 2.03 ± 1.46 | .182                             | 2.92 ± 1.62 | .298                             |
| 67. To find meaning in my loss                             | 4.56 ± 0.94 | .483                             | 3.40 ± 1.48 | .450                             |
| 68. To have hope for the future                            | 4.66 ± 0.74 | .392                             | 3.71 ± 1.31 | .407                             |

<sup>a</sup>Items are listed in the order presented to respondents.

**Table 3**  
**Bereaved Parent Needs Assessment scale statistics, correlations, and reliabilities**

| Bereaved Parent Needs Assessment Scale | Correlations     |                   |       | Scale Statistics |  |
|--|------------------|-------------------|-------|------------------|--|
|  | Total Importance | Total Fulfillment | Mean  | sd               | Reliability (95% Confidence Interval) <sup>a</sup> |
| Total importance                       |                  |                   | 86.95 | 10.38            | 0.92 (0.90–0.94)                                   |
| Total fulfillment                      | .27 <sup>b</sup> |                   | 80.74 | 15.91            | 0.92 (0.90–0.94)                                   |
| Percent fulfillment                    | .16              | .96 <sup>c</sup>  | 83.73 | 15.97            | 0.94 (0.91–0.96)                                   |

<sup>a</sup> Cronbach's  $\alpha$  was used for the Total Importance and Total Fulfillment Scales; Spearman-Brown–corrected split-half reliability was used for the Percent Fulfillment Scale;

<sup>b</sup>  $p < .05$ ;

<sup>c</sup>  $p < .001$ .

**Table 4**  
**Correlations of demographic and clinical variables with the Bereaved Parent Needs Assessment Scales, Inventory of Complicated Grief and World Health Organization Quality of Life Questionnaire**

|                                      | Total Importance | Total Fulfillment | Percent Fulfillment | Inventory of Complicated Grief | World Health Organization Quality of Life questionnaire |
|--------------------------------------|------------------|-------------------|---------------------|--------------------------------|---|
| Parent age (yrs), n = 118            |                  |                   |                     |                                |   |
| Pearson correlation                  | .171             | .250              | .239                | -.163                          | .105  |
| Significance <sup>a</sup>            | .065             | .006              | .009                | .077                           | .258  |
| Parent gender (female), n = 121      |                  |                   |                     |                                |   |
| Pearson correlation                  | .200             | -.202             | -.212               | .049                           | -.057   |
| Significance                         | .028             | .026              | .020                | .593                           | .537  |
| Parent race (white), n = 121         |                  |                   |                     |                                |   |
| Pearson correlation                  | .006             | .005              | -.056               | -.035                          | .076  |
| Significance                         | .947             | .952              | .542                | .707                           | .405  |
| Parent ethnicity (Hispanic), n = 121 |                  |                   |                     |                                |   |
| Pearson correlation                  | -.176            | -.204             | -.132               | .045                           | -.025   |
| Significance                         | .054             | .025              | .150                | .626                           | .788  |
| Marital status (married), n = 121    |                  |                   |                     |                                |   |
| Pearson correlation                  | -.107            | .047              | .031                | -.123                          | .175  |
| Significance                         | .244             | .607              | .732                | .177                           | .054  |
| Education (yrs), n = 121             |                  |                   |                     |                                |   |
| Pearson correlation                  | .029             | .217              | .216                | -.411                          | .290  |
| Significance                         | .754             | .017              | .018                | .000                           | .001  |
| Biological parent, n = 120           |                  |                   |                     |                                |   |
| Pearson correlation                  | -.074            | -.122             | -.137               | .262                           | -.087   |
| Significance                         | .422             | .185              | .136                | .004                           | .344  |
| Loss of only child, n = 121          |                  |                   |                     |                                |   |
| Pearson correlation                  | -.226            | -.241             | -.199               | .173                           | -.021   |
| Significance                         | .013             | .008              | .028                | .057                           | .823  |
| Child age (yrs), n = 121             |                  |                   |                     |                                |   |
| Pearson correlation                  | .220             | .143              | .121                | .078                           | .013  |
| Significance                         | .015             | .118              | .186                | .398                           | .889  |
| Child gender (female), n = 121       |                  |                   |                     |                                |   |



|   | Total Importance | Total Fulfillment | Percent Fulfillment | Inventory of Complicated Grief | World Health Organization Quality of Life questionnaire |
|---|------------------|-------------------|---------------------|--------------------------------|---|
| Pearson correlation                                     | .099             | .085              | .081                | -.032                          | .144  |
| Significance  | .282             | .355              | .379                | .729                           | .116  |
| Cause of death (trauma), n = 121                        |                  |                   |                     |                                |   |
| Pearson correlation                                     | -.016            | -.067             | -.048               | .234                           | -.106   |
| Significance  | .858             | .467              | .604                | .010                           | .246  |
| Hospital admissions (no.), n = 120                      |                  |                   |                     |                                |   |
| Pearson correlation                                     | .073             | .131              | .079                | -.072                          | .148  |
| Significance  | .430             | .155              | .393                | .432                           | .106  |
| Pediatric intensive care unit admissions (no.), n = 119 |                  |                   |                     |                                |   |
| Pearson correlation                                     | .066             | .145              | .088                | -.045                          | .050  |
| Significance  | .475             | .116              | .341                | .629                           | .590  |
| Pediatric intensive care unit length of stay, n = 121   |                  |                   |                     |                                |   |
| Pearson correlation                                     | -.141            | .107              | .129                | -.187                          | .103  |
| Significance  | .122             | .245              | .160                | .040                           | .262  |

<sup>a</sup> All significance levels are two-tailed.

**Table 5**  
**Correlations and adjusted correlations of the Bereaved Parent Needs Assessment Scales with Inventory of Complicated Grief and World Health Organization Quality of Life Questionnaire**

|                     | Correlations      |   | Adjusted Correlations <sup>a</sup> |   | 95% Confidence Interval for ICG Adjusted Correlation <sup>b</sup> |       |
|---------------------|-------------------|---|------------------------------------|---|---|-------|
|                     | ICG               | World Health Organization Quality of Life questionnaire | ICG                                | World Health Organization Quality of Life questionnaire | Upper   | Lower |
| Total importance    | .10               | .03   | .13                                | -.02  | -.01  | .28   |
| Total fulfillment   | -.29 <sup>c</sup> | .21 <sup>d</sup>  | -.18                               | .17   | -.37  | .01   |
| Percent fulfillment | -.31 <sup>c</sup> | .21 <sup>d</sup>  | -.21 <sup>d</sup>                  | .17   | -.41  | -.02  |

ICG, Inventory of Complicated Grief.

<sup>a</sup> Adjusted for parent's age, education, and loss of only child;

<sup>b</sup> confidence interval uses Huber-White robust standard error from generalized estimating equation model;

<sup>c</sup>  $p < .01$ ;

<sup>d</sup>  $p < .05$ .