

# Association of Illness Severity With Family Outcomes Following Pediatric Septic Shock

**IMPORTANCE:** It is unknown which families are at risk for poor outcomes following a child's critical illness.

**OBJECTIVES:** To evaluate if pediatric septic shock severity is associated with caregiver distress and family dysfunction throughout the year postadmission and if caregiver outcomes are associated with child health-related quality of life (HRQL).

**DESIGN, SETTING, AND PARTICIPANTS:** Secondary analysis of the Life After Pediatric Sepsis Evaluation prospective cohort study among children less than 18 years old with community-acquired septic shock requiring vasoactive-inotropic support and invasive or noninvasive ventilation in 12 academic U.S. PICUs.

**MAIN OUTCOMES AND MEASURES:** Caregivers reported personal psychologic distress (Brief Symptom Inventory), family functioning (Family Assessment Device), and child HRQL (Pediatric Quality of Life Inventory, Functional Status II-Revised) at baseline and 1, 3, 6, and 12 months following PICU admission.

**RESULTS:** Among 276 caregivers, psychologic distress prevalence initially decreased then rose to 15.3%, whereas prevalence of family dysfunction increased steadily to 30.9% at 12 months. On multivariable logistic regression adjusting for patient age, medical complexity, and immunosuppression, higher Pediatric Risk of Mortality and vasoactive-inotropic scores and longer PICU and hospital stay were associated with greater caregiver distress at 1 month. Higher Pediatric Logistic Organ Dysfunction (PELOD) score, longer ventilation, and longer PICU stay were associated with lower odds of family dysfunction at 1, 3, and 6 months (average PELOD vs new 6-mo dysfunction: odds ratio [OR], 0.73 [95% CI, 0.55–0.96]). Caregiver distress was associated with child HRQL decline from baseline to 1 month (OR, 2.92 [1.27–6.75]), 3 months (OR, 2.34 [1.01–5.42]), and 12 months (OR, 3.94 [1.54–10.06]).

**CONCLUSIONS AND RELEVANCE:** Family dysfunction becomes increasingly prevalent over the year following pediatric septic shock and is less likely following higher severity illness. Caregiver psychologic distress is associated with worse child HRQL. Both patients and families may benefit from ongoing psychosocial support following survival from pediatric septic shock.

**KEY WORDS:** caregivers; health-related quality of life; intensive care units; pediatric; psychologic distress; septic; shock

Although it is increasingly well recognized that children surviving sepsis are at risk for a range of postdischarge morbidities (1–5), the effects of a child's critical illness are not limited to the patient. Many family members experience post-traumatic stress, depression, and anxiety (6–8) and disruptions in family functioning (9) that may persist for months following their child's PICU hospitalization (6, 10). The recent Life After Pediatric Sepsis Evaluation (LAPSE) multicenter prospective cohort study (11) demonstrated that one-quarter of caregivers of children surviving septic shock reported symptoms consistent with moderate-to-high distress 1 year following their

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child's hospitalization, and over 30% experienced deterioration in their family functioning during that year (12). It remains unclear, however, how to identify the highest risk families to better target family-related support and interventions.

LAPSE identified multiple illness severity measures strongly associated with persistent, serious deterioration of a child's health-related quality of life (HRQL) compared with baseline following admission for septic shock (13). Although surviving a high-severity illness may indicate that a child warrants close postdischarge follow-up, it is unknown whether these are also the families at highest risk for poor outcomes; associations between objective measures of illness severity and parental distress in other PICU populations have been inconsistent (7). In this study, we aimed to determine the association between illness severity with caregiver distress and family dysfunction following a child's PICU admission for septic shock. Our secondary objective was to evaluate whether caregiver distress and family functioning were associated with child HRQL. We hypothesized that families whose children were more severely ill would more commonly experience distress and dysfunction, and that caregivers reporting greater distress and family dysfunction would more commonly report poor child HRQL.

## MATERIALS AND METHODS

### Study Design and Participants

This was a secondary analysis of the LAPSE prospective cohort study conducted in 12 academic U.S. PICUs from January 1, 2014, to June 30, 2017 to evaluate patient and family outcomes following community-acquired septic shock. Detailed methods have previously been described (11). Inclusion criteria were: 1) age 44 weeks of gestation to less than 18 years, 2) documented or suspected infection within 48 hours of hospital admission, 3) greater than or equal to 2/4 systemic inflammatory response syndrome criteria (14), 4) cardiovascular dysfunction with vasoactive-inotropic support, and 5) pulmonary dysfunction with invasive or noninvasive ventilation. Patients were excluded if they had sustained burns, they had limitation of care orders, their parents/guardians were not English- or Spanish-speaking, or they were wards of the state. Caregivers completed assessments of their own psychologic and family functioning and their child's HRQL at enrollment to reflect

a baseline status during the month prior to admission. Caregivers of surviving children were contacted by phone or e-mail to complete follow-up assessments at 1, 3, 6, and 12 months following PICU admission. The study was approved by the University of Utah central Institutional Review Board (00069155, February 1, 2014, LAPSE). Informed consent was obtained from all participants, and procedures were in accordance with the ethical standards of the Institutional Review Board and with the Helsinki Declaration of 1975. We adhered to the Strengthening the Reporting of Observational Studies in Epidemiology guidelines for cohort studies (15) (**Supplemental Table 1**, <http://links.lww.com/CCX/B12>).

### Measures

Illness severity was assessed using admission Pediatric Risk of Mortality (PRISM)-III (16) score, daily Pediatric Logistic Organ Dysfunction (PELOD)-2 (17) score, twice daily Vasoactive-Inotropic Score (VIS) (18), duration of invasive ventilation, and PICU and hospital length of stay (LOS).

Family outcomes included caregiver psychologic distress and family dysfunction. Caregiver psychologic functioning was assessed with the Brief Symptom Inventory (BSI)-18 (19). The BSI-18 has demonstrated reliability and validity across multiple settings (19) and has been used to assess parent psychologic distress following pediatric hospitalization (20). It consists of 18 items assessing somatization, depression, and anxiety. One item assessing suicidality was not included for this study. A total score of greater than or equal to 20 or two positive domain scores (somatization  $\geq 6$ , depression  $\geq 7$ , and anxiety  $\geq 7$ ) indicate clinically relevant psychologic distress (19).

The 12-item General Functioning Scale of the McMaster Family Assessment Device (FAD) (21) was used to assess family functioning. The FAD has demonstrated reliability and validity in multiple pediatric settings (22–24). A score of greater than or equal to 2 indicates dysfunction (21).

Caregivers completed assessments of their child's HRQL using the Pediatric Quality of Life Inventory (PedsQL) 4.0 Generic Core Scales (25) or Infant Scales (26), or the Functional Status II-Revised (FS II-R) (27). The PedsQL scales have frequently been used in PICU settings (28–30), and multiple studies have established use of recall to estimate patients' baseline HRQL (31–33). The FS II-R is a validated measure of pediatric

general health and has been considered an HRQL measure for children with severe developmental disabilities (34). Both measures are scored on a 0–100 scale, with higher scores indicating better HRQL. The minimum clinically important difference for the PedsQL is 4.5 points (25), and the same has been employed for the FS II-R (11).

All caregiver and child measures were assessed at baseline (per a recall assessment of the month prior to admission) and 1, 3, 6, and 12 months following PICU admission.

## Statistical Analysis

The sample of patients whose caregivers completed a baseline and at least one follow-up BSI or FAD survey constituted the study cohort. We compared characteristics of the study cohort with those of participants who survived but did not complete a follow-up BSI or FAD using chi-square tests for categorical variables and Wilcoxon rank-sum tests for continuous variables. To assess differences due to attrition, we used the same methods to compare the characteristics of participants with surveys completed at early follow-up time points (1 or 3 mo) and at later time points (6 or 12 mo) to participants with surveys completed at early but not later time points. We calculated the percentage of respondents with positive BSI and FAD scores at each time point. We performed multiple imputation using chained equations with 10 iterations to impute patient and family characteristics with missing data. The only variable with greater than 3% missing data was patient race, with 7.3% missingness. We conducted bivariate logistic regression models using the imputed data evaluating associations between patient and family characteristics with baseline BSI and FAD score, psychologic distress (positive BSI score) at any follow-up time point, and new family dysfunction (FAD score >2 among families with baseline FAD score <2) at any follow-up time point. New psychologic distress was uncommon and thus not examined as a primary outcome in regression models.

We performed multivariable logistic regression evaluating associations between positive BSI and FAD, and between measures of illness severity with psychologic distress and new family dysfunction at each follow-up time point, adjusted for a priori-determined potential confounders of patient age, baseline

Pediatric Medical Complexity Algorithm (PMCA) category (35), and immunocompromise. No additional variables were identified on bivariate analyses as potential confounders (**Supplemental Table 2**, <http://links.lww.com/CCX/B12>). Finally, we evaluated the association between caregiver psychologic distress or family dysfunction and child HRQL at each time point using linear regression models for total change in child HRQL score and logistic regression models for decline in child HRQL by greater than or equal to 4.5 points from baseline, with all models adjusted for patient age, baseline PMCA category, immunocompromise, and maximum PELOD score. All analyses were performed using Stata SE 14.2 (StataCorp LP, College Station, TX).

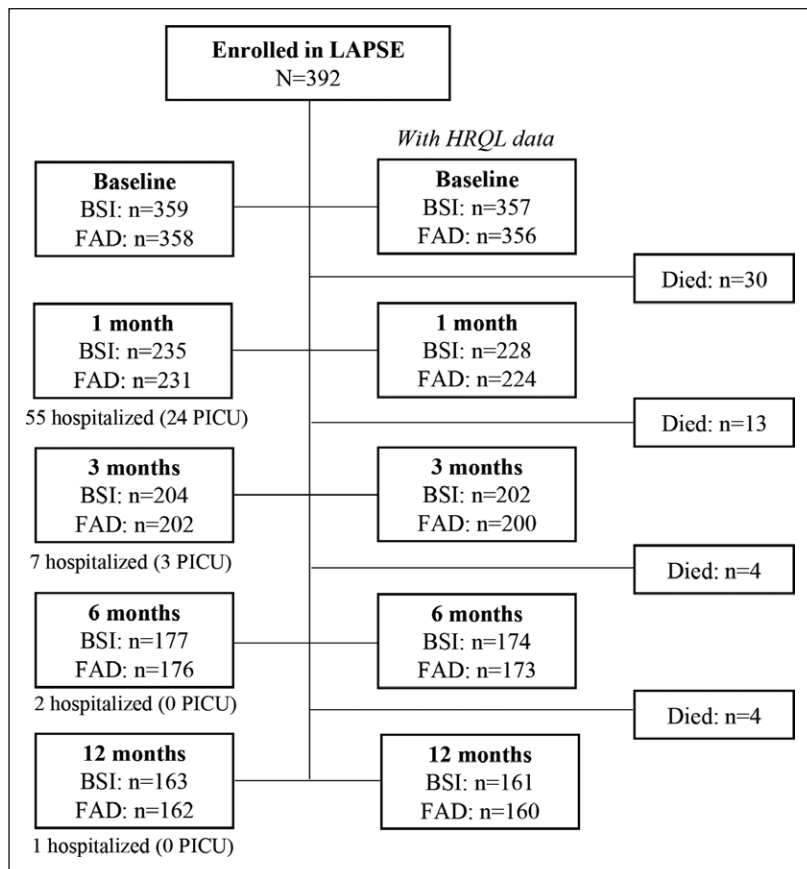
## RESULTS

### Cohort Characteristics

Of 392 patients enrolled in LAPSE, 276 participants had a baseline and at least one follow-up BSI or FAD and constituted the study cohort (**Fig. 1**). Compared with participants who survived but did not complete a follow-up BSI or FAD, study patients had a longer hospital LOS but were otherwise not significantly different (**Supplemental Table 3**, <http://links.lww.com/CCX/B12>). At 1-month follow-up, 23.4% of patients with completed surveys were still hospitalized including 10.2% in the PICU; 3.4% of respondents were still hospitalized at 3-month follow-up (**Fig. 1**). Among participants with follow-up surveys completed at early time points, those with attrition by 6 or 12 months were more likely to be Hispanic, have lower household income, and have worse baseline Functional Status Scale score than participants who were retained through these later time points (**Supplemental Table 4**, <http://links.lww.com/CCX/B12>).

### Trajectory of Family Outcome Measures

The percentage of caregivers with psychologic distress was highest at baseline (28.4%) and decreased to a nadir of 9.6% at 6 months before increasing back up to 15.3% at 12 months (**Supplemental Fig. 1A**, <http://links.lww.com/CCX/B12>). The most commonly involved domain at almost all time points was anxiety, with 35.6% of respondents having a positive score at baseline and 17.8% at 12 months. The percentage of respondents without psychologic distress at baseline who later



**Figure 1.** Flow diagram of participants included in Life After Pediatric Sepsis Evaluation (LAPSE) with follow-up data. BSI = brief symptom inventory, FAD = family assessment device, HRQL = health-related quality of life.

developed psychological distress decreased at each of the first three follow-up time points from 6.8% at 1 month to 5.4% at 3 months and 4.0% at 6 months, but increased to 8.6% at 12 months (**Supplemental Fig. 1B**, <http://links.lww.com/CCX/B12>). The percentage of respondents with family dysfunction increased over the follow-up period from 21.7% at baseline to a peak of 30.9% at 12 months (**Supplemental Fig. 1C**, <http://links.lww.com/CCX/B12>). The percentage of respondents with new family dysfunction increased at each follow-up time point from 10.7% at 1 month to 19.1% at 12 months (**Supplemental Fig. 1D**, <http://links.lww.com/CCX/B12>). Psychological distress was associated with family dysfunction at 12 months (odds ratio [OR], 2.92; 95% CI, 1.20–7.11) but not at any other time point.

### Association of Patient and Family Characteristics With Family Outcomes

No patient or family characteristics were associated with baseline caregiver psychological distress (**Supplemental Table 5**, <http://links.lww.com/CCX/>

B12). Hispanic ethnicity, public or no insurance, patient complex chronic condition or worse Functional Status Scale (36) score, and annual household income were associated with baseline family dysfunction on bivariate analyses (**Supplemental Table 5**, <http://links.lww.com/CCX/B12>). No sociodemographic characteristics were significantly associated with psychological distress or new family dysfunction at any follow-up time point (**Supplemental Table 2**, <http://links.lww.com/CCX/B12>).

### Association of Illness Severity With Family Outcomes

Higher PRISM score, higher maximum VIS, and longer PICU and hospital LOS were all associated with presence of psychological distress at 1 month after adjustment for patient age, baseline PMCA category, and immunocompromise (**Table 1**). No illness severity measures were associated with psychological distress at any other follow-up time points.

After adjustment, higher day 1 PELOD, higher maximum PELOD, and longer duration of ventilation were all associated with lower odds of new family dysfunction at 1 month compared with baseline (**Table 2**). A similar association was found for higher maximum PELOD and longer ventilation at 3-month follow-up. At 6 months, multiple factors were associated with lower odds of new family dysfunction: higher day 1 PELOD, higher maximum PELOD, higher average PELOD, longer ventilation, and longer PICU LOS. The strongest associations between in-hospital factors and new family dysfunction were observed at 6 months, with odds of new family dysfunction 27% lower for every 1 point increase in average PELOD (OR, 0.73; 95% CI, 0.55–0.96) and 21% lower for every 1 point increase in maximum PELOD (OR, 0.79; 95% CI, 0.68–0.93).

### Association of Family Outcomes With Child HRQL

Patients whose caregivers had baseline psychological distress had a mean baseline proxy-reported HRQL score 6.6 points lower than patients whose caregivers did not have baseline psychological distress (95% CI,

**TABLE 1.**

**Association Between Illness Severity Measures and Caregiver Psychologic Distress (Positive Brief Symptom Inventory Score) at Each Follow-Up Time Point, Adjusted for Patient Age, Baseline Pediatric Medical Complexity Algorithm Category, and Immunocompromise**

Illness Severity Measure	1 mo	3 mo	6 mo	12 mo
	aOR (95% CI)	aOR (95% CI)	aOR (95% CI)	aOR (95% CI)
Pediatric Risk of Mortality score	<b>1.04 (1.00–1.08)</b>	0.99 (0.94–1.04)	1.05 (0.99–1.12)	0.97 (0.92–1.03)
Day 1 PELOD score	1.07 (0.96–1.20)	1.00 (0.88–1.14)	1.06 (0.91–1.23)	0.98 (0.84–1.15)
Maximum PELOD score	1.07 (0.97–1.19)	1.00 (0.89–1.12)	1.13 (0.98–1.31)	0.94 (0.82–1.08)
Average PELOD score	1.15 (0.93–1.42)	0.97 (0.76–1.24)	0.98 (0.74–1.32)	1.09 (0.82–1.46)
Day 1 VIS	1.02 (0.99–1.04)	1.01 (0.99–1.04)	1.01 (0.99–1.04)	1.00 (0.97–1.03)
Maximum VIS	<b>1.02 (1.00–1.04)</b>	1.01 (0.99–1.04)	1.02 (0.99–1.05)	1.01 (0.98–1.04)
Average VIS	1.05 (0.98–1.11)	1.01 (0.94–1.10)	1.00 (0.90–1.11)	1.03 (0.95–1.11)
Ventilator days	1.01 (0.96–1.05)	1.02 (0.98–1.07)	1.04 (0.97–1.11)	1.00 (0.94–1.06)
PICU length of stay	<b>1.01 (1.00–1.03)</b>	1.00 (0.98–1.02)	1.03 (0.99–1.06)	1.01 (0.98–1.04)
Hospital length of stay	<b>1.01 (1.00–1.02)</b>	1.00 (0.99–1.01)	1.00 (0.99–1.01)	1.00 (0.99–1.01)

aOR = adjusted odds ratio, PELOD = Pediatric Logistic Organ Dysfunction, VIS = Vasoactive-Inotropic Score. Boldface value indicates a statistically significant association.

**TABLE 2.**

**Association Between Illness Severity Measures and New Family Dysfunction (Family Assessment Device Score <2 at Baseline and ≥2 at Follow-Up) at Each Follow-Up Time Point, Adjusted for Patient Age, Baseline Pediatric Medical Complexity Algorithm Category, and Immunocompromise**

Illness Severity Measure	1 mo	3 mo	6 mo	12 mo
	aOR (95% CI)	aOR (95% CI)	aOR (95% CI)	aOR (95% CI)
Pediatric Risk of Mortality score	1.02 (0.98–1.08)	0.98 (0.92–1.03)	0.98 (0.92–1.03)	0.97 (0.92–1.02)
Day 1 PELOD score	<b>0.80 (0.67–0.96)</b>	0.87 (0.74–1.03)	<b>0.85 (0.72–0.99)</b>	0.96 (0.85–1.10)
Maximum PELOD score	<b>0.84 (0.72–0.97)</b>	<b>0.85 (0.73–0.98)</b>	<b>0.79 (0.68–0.93)</b>	0.93 (0.83–1.04)
Average PELOD score	0.82 (0.64–1.06)	1.01 (0.77–1.32)	<b>0.73 (0.55–0.96)</b>	0.99 (0.78–1.26)
Day 1 VIS	1.00 (0.97–1.02)	1.00 (0.97–1.03)	0.99 (0.96–1.02)	0.99 (0.96–1.02)
Maximum VIS	0.99 (0.97–1.02)	1.00 (0.97–1.03)	0.99 (0.96–1.02)	0.98 (0.95–1.02)
Average VIS	1.00 (0.93–1.08)	1.05 (0.98–1.13)	0.97 (0.88–1.07)	0.92 (0.80–1.06)
Ventilator days	<b>0.94 (0.89–0.99)</b>	<b>0.93 (0.86–0.99)</b>	<b>0.90 (0.82–0.99)</b>	0.97 (0.91–1.03)
PICU length of stay	0.98 (0.95–1.01)	0.96 (0.92–1.01)	<b>0.92 (0.85–0.99)</b>	0.96 (0.92–1.01)
Hospital length of stay	0.98 (0.96–1.01)	0.98 (0.95–1.01)	1.00 (0.98–1.01)	0.97 (0.94–1.00)

aOR = adjusted odds ratio, PELOD = Pediatric Logistic Organ Dysfunction, VIS = Vasoactive-Inotropic Score. Boldface values indicate a statistically significant association.

-10.5 to -2.7). Children in families with baseline dysfunction had a mean baseline HRQL score 7.8 points lower than patients without family dysfunction (95% CI, -12.0 to -3.6).

At each follow-up time point, the percentage of patients with clinically important decline in proxy-reported HRQL from baseline ( $\geq 4.5$  points) was greater among patients whose caregivers had psychologic distress at that time point than patients whose caregivers did not have psychologic distress, most notably at 1 month (70.6% vs 46.4%), 3 months (53.3% vs 34.3%), and 12 months (56.0% vs 29.4%). After adjustment for patient age, medical complexity, immunosuppression, and illness severity, the odds of a clinically important decline in caregiver-reported child HRQL from baseline was significantly higher for patients whose caregivers had psychologic distress at 1, 3, and 12 months (Fig. 2). The prevalence of child HRQL decline at each time point was highest among patients whose caregivers developed new psychologic distress from baseline compared with those who had persistent distress, whose baseline distress resolved, or who never had distress (Supplemental Fig. 2, <http://links.lww.com/CCX/B12>).

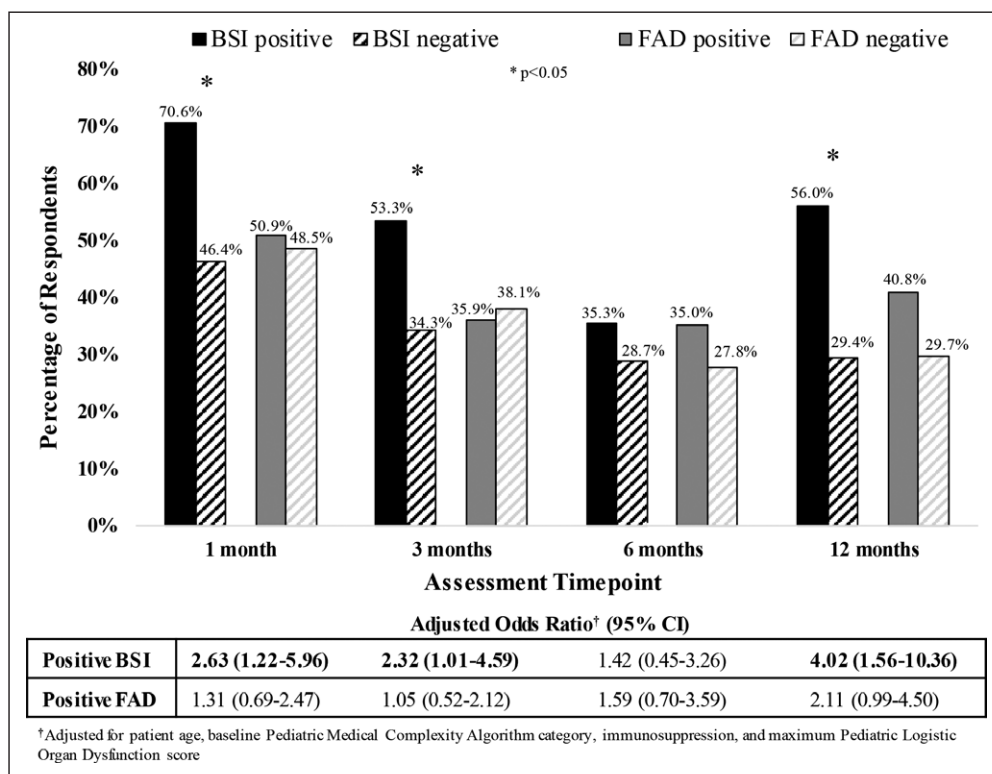
There was no association between child HRQL and family dysfunction at any follow-up time point. At 12 months, the prevalence of child HRQL decline was higher in families with dysfunction (40.8% vs 29.7%), but this did not reach statistical significance after adjustment (adjusted OR [aOR], 2.11; 95% CI, 0.99-4.50).

## DISCUSSION

The importance of family outcomes in pediatric critical care has been highlighted as a core component of Postintensive Care Syndrome-pediatrics (37), and the International Guidelines for Management of Sepsis and Septic Shock identify the promotion of family-centered care as a priority (38). This study of 276 families followed for up to 1 year following their child's PICU admission for community-acquired septic shock is the largest evaluation of the association between a child's illness severity and family outcomes. We found that although caregiver distress, particularly anxiety, generally decreases over time, family dysfunction becomes increasingly prevalent over the year following the

child's hospitalization with nearly one-third of families reporting dysfunction. Interestingly, higher illness severity was associated with lower odds of family dysfunction throughout the first 6 months following PICU admission. In contrast, the child's illness severity was associated with greater caregiver psychologic distress at 1 month following admission but not at later time points.

Our finding that the proportion of caregivers with psychologic distress increased at 12 months after decreasing steadily over the prior three time points is consistent with literature demonstrating that many caregivers experience delayed responses



**Figure 2.** Prevalence of decline in proxy-reported health-related quality of life (HRQL) from baseline ( $\geq 4.5$  points) by presence or absence of caregiver distress (Brief Symptom Inventory [BSI]) and family dysfunction (Family Assessment Device [FAD]), with odds ratios for HRQL decline with a positive relative to a negative BSI or FAD.

following their child's critical illness (6, 10, 39). There was a small but important number of caregivers who experienced greater distress following their child's hospitalization than at the time of admission, and this group increased to 8.6% of caregivers by 1 year after admission. Qualitative work suggests that parents may focus on their child's physical recovery immediately following a PICU stay, and only later can they begin their own emotional processing of the experience (40). However, identifying the caregivers at highest risk for prolonged distress is challenging; we did not observe any patient or family characteristics associated with caregiver distress during the follow-up period, and consistent with prior work (7), no measures of illness severity were associated with caregiver distress beyond 1-month follow-up.

The dual findings that the prevalence of family dysfunction increased throughout the year following a child's critical illness and that greater illness severity was associated with lower odds of dysfunction may be related. Families experiencing a severe stressor may come together to cope, thus improving family dynamics during the time that the child was most severely ill. Although studies have not demonstrated a consistent association between a child's illness severity and family outcomes (41), our findings could be explained by families of severely ill children having a greater opportunity to experience post-traumatic growth (42). Previous work found greater post-traumatic growth among parents of mechanically ventilated children than parents of nonventilated children (43), parents who perceived their children to have higher illness severity (44), and parents who experienced greater acute stress during the ICU stay (44, 45). Over time, however, perhaps as a child continued to experience morbidities including previously unrecognized or emerging psychosocial HRQL dysfunction, family functioning may have deteriorated without the acute stressor to bring them together. Additionally, families whose children experienced a more severe illness may have received greater postdischarge supports from the healthcare system or community that waned over time. Qualitative assessments of these families may be a particularly effective way to enrich our understanding of effective coping strategies and post-traumatic growth among families supporting a critically ill child (46).

Importantly, we found that baseline caregiver distress was strongly associated with lower baseline child

HRQL scores by caregiver proxy-report. Caregiver distress was also strongly associated with greater prevalence of child HRQL decline from baseline at multiple follow-up time points throughout the first year following PICU admission even after adjustment for illness severity, most notably at 12 months with four times the odds of HRQL decline among children whose caregivers had psychologic distress. Given that these assessments were obtained cross-sectionally, it is challenging to know the extent to which poor child HRQL contributed to greater caregiver distress or that caregiver distress could have led to proxy-reporting biased toward worse quality of life. Multiple studies of pediatric cancer patients have demonstrated a correlation between parental distress and child HRQL (47), and a parent's own quality of life is associated with their proxy-reporting of their child's HRQL in both healthy children (48) and children with cancer (49). As is commonly the case in the PICU (29), child self-report of HRQL is difficult to obtain due to age, critical illness, sedation, and neurologic disability, and thus we are unable to compare self-reported HRQL with proxy-reports. Better understanding of how caregivers' psychologic status may influence their perspective on their child's quality of life, including parallel assessment of child self-report and parent proxy-report when possible, comparison of HRQL assessments by different caregivers, and qualitative interviews should be a research priority especially given this dependence on proxy-reporting.

The lack of association between family functioning and child HRQL, and the lack of association between psychologic distress and family dysfunction at all but a single time point, suggest that the overall cohesion of the family and the individual psychologic well-being of a caregiver are distinct entities and thus likely require different interventions. Although bereavement support for families after the death of a child in the PICU has been relatively well studied (50), there is less known about how to support caregivers of surviving children. Improved availability of psychologic evaluation and support teams for both patients and families, enhanced family-centered care to facilitate family presence and communication (51), and better communication between PICU and outpatient providers may all be effective strategies to improve family outcomes; even improved rehabilitation services for patients may help to reduce caregiver stress (52).

There were several limitations to this study. There was substantial participant attrition over the follow-up period, and although there were few significant differences between patients who did and did not contribute follow-up data, there were several differences in patient and family characteristics between patients with and without attrition by later follow-up time points. Baseline assessment of both child HRQL and caregiver outcomes were based on recall, which is inherently subject to bias. The direction of recall bias is unknown and likely variable; some caregivers may have recalled the preadmission state of their child, self, or family to have been better than it actually was, whereas others may have been influenced by the acute illness such that they recalled baseline to be worse than it was. In particular, high caregiver distress scores at baseline may reflect psychologic status at admission rather than pre-illness despite having been instructed to report their status prior to the onset of the illness. Additionally, we do not have data on outcomes of families whose children died prior to follow-up.

## CONCLUSIONS

This study enhances our understanding of the ongoing burden of sepsis experienced by families in addition to their critically ill children, with psychologic distress and family dysfunction persisting for up to a year following PICU admission for many families. It also highlights the importance of ongoing longitudinal follow-up following PICU care, as the rising prevalence of caregiver distress and impaired child HRQL at 12 months would not have been observed with a shorter follow-up time period. Our findings that greater illness severity may be associated with improved family functioning during this time period and that the presence of caregiver psychologic distress is strongly related to proxy-reporting of poor child HRQL are novel, and both warrant additional study to help optimize recovery of both children and families following pediatric critical illness.

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