

# Longitudinal Trajectories of Caregiver Distress and Family Functioning After Community-Acquired Pediatric Septic Shock

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**Objectives:** To identify trajectories and correlates of caregiver distress and family functioning in families of children who survived community-acquired septic shock. We hypothesized that: 1) a substantial subset of families would demonstrate trajectories of persistent elevated caregiver distress and impaired family functioning 12 months after hospitalization and 2) sociodemographic and clinical risk factors would be associated with trajectories of persistent distress and family dysfunction.

**Design:** Prospective cohort.

**Setting:** Fourteen PICUs in the United States.

**Patients:** Caregivers of 260 children who survived community-acquired septic shock.

**Interventions:** None.

**Measurements and Main Results:** Caregivers completed ratings of distress on the Brief Symptom Inventory and of family functioning on the Family Assessment Device at baseline, 1, 3, 6, and 12 months after hospitalization. Results from group-based trajectory modeling indicated that 67% of the current sample was characterized by persistent low caregiver distress, 26% by persistent moderate to high distress that remained stable across 12 months (high-risk caregiver distress group), and 8% by initial high distress followed by gradual recovery. Forty percent of the sample was characterized by stable high family functioning, 15% by persistent high dysfunction across 12 months (high-risk family functioning group), 12% by gradually improving functioning, and 32% by deteriorating function over time. Independently of age, child race was associated with membership in the high-risk caregiver distress group (non-white/Hispanic; effect size,  $-0.12$ ;  $p = 0.010$ ). There were no significant sociodemographic or clinical correlates of the high-risk family functioning group in multivariable analyses.

**Conclusions:** Although the majority of families whose children survived community-acquired septic shock were characterized by resilience, a subgroup demonstrated trajectories of persistently elevated distress and family dysfunction during the 12 months after hospitalization. Results suggest a need for family-based psychosocial screening after pediatric septic shock to identify and support at-risk families. (*Pediatr Crit Care Med* 2020; 21:787–796)

**Key Words:** caregiver; critical care; distress; family functioning; pediatrics; sepsis

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Community-acquired septic shock is a frequent cause of PICU hospitalization with rates of hospital mortality up to 10% (1–4). Pediatric septic shock is associated with a range of possible neurologic, cognitive, and physical health changes following hospitalization and often requires intensive medical follow-up that poses a significant burden on families (5–7). Characterizing family outcomes after pediatric

septic shock is particularly important given that International Guidelines for Management of Sepsis and Septic Shock identify the promotion of family-centered care as a priority (8). Systematic reviews of pediatric critical illness have called for longitudinal studies to elucidate trajectories and factors associated with family functioning over time to inform future family-level prevention and intervention approaches (9–12).

Similar to what has been found in other child health conditions (13–15), child and family well-being are intertwined where a child's recovery from critical illness may be optimized by healthy family functioning, and in turn, family functioning may be impacted by a child's critical illness. Previous studies have shown that caregivers are at risk for elevated rates of distress symptoms; furthermore, family functioning often declines following an acute pediatric injury or hospitalization (10, 16–21). However, little is known about long-term trajectories of caregiver and family functioning following PICU hospitalization for pediatric septic shock specifically. Similar to findings in other acute pediatric illness populations (22, 23), it is possible that disruptions in caregiver and family functioning may persist well after hospitalization for a substantial portion of families.

There are also gaps in knowledge about risk factors for increased caregiver distress and poor family functioning following hospitalization for pediatric septic shock. Models of family adjustment to pediatric illness suggest that child, family, and systems level determinants all contribute to family functioning over time (24). Previous studies of outcomes after PICU admission have identified predictors of impairment in child functioning that include sociodemographic characteristics (child age, sex, race/ethnicity, caregiver sex, and education level) as well as medical characteristics (length of PICU stay and severity of illness) (9–11, 19, 25–27). Similar sociodemographic and medical predictors may also be associated with impairment in caregiver and family functioning after pediatric septic shock but have not as yet been studied.

The purpose of this study was to identify the course and factors associated with caregiver and family outcomes after a child's PICU admission for community-acquired septic shock to inform screening and prevention efforts. We hypothesized that a substantial subset of families of survivors of pediatric septic shock would demonstrate persistent elevated caregiver distress and impaired family functioning 12 months after hospitalization. Our secondary hypothesis was that younger child age, female sex, sociodemographic risk (racial/ethnic minority, lower caregiver education level, insurance through Medicaid, lower household income, and single-parent status), medical complexity/chronic condition, chronic device use, neurologic insult, and PICU length of stay would be associated with trajectories of persistent caregiver distress and family dysfunction at 1, 3, 6, and 12 months after hospitalization.

## MATERIALS AND METHODS

### Procedure

This is a secondary analysis from Life After Pediatric Sepsis Evaluation (LAPSE) (3, 4), a multisite prospective cohort

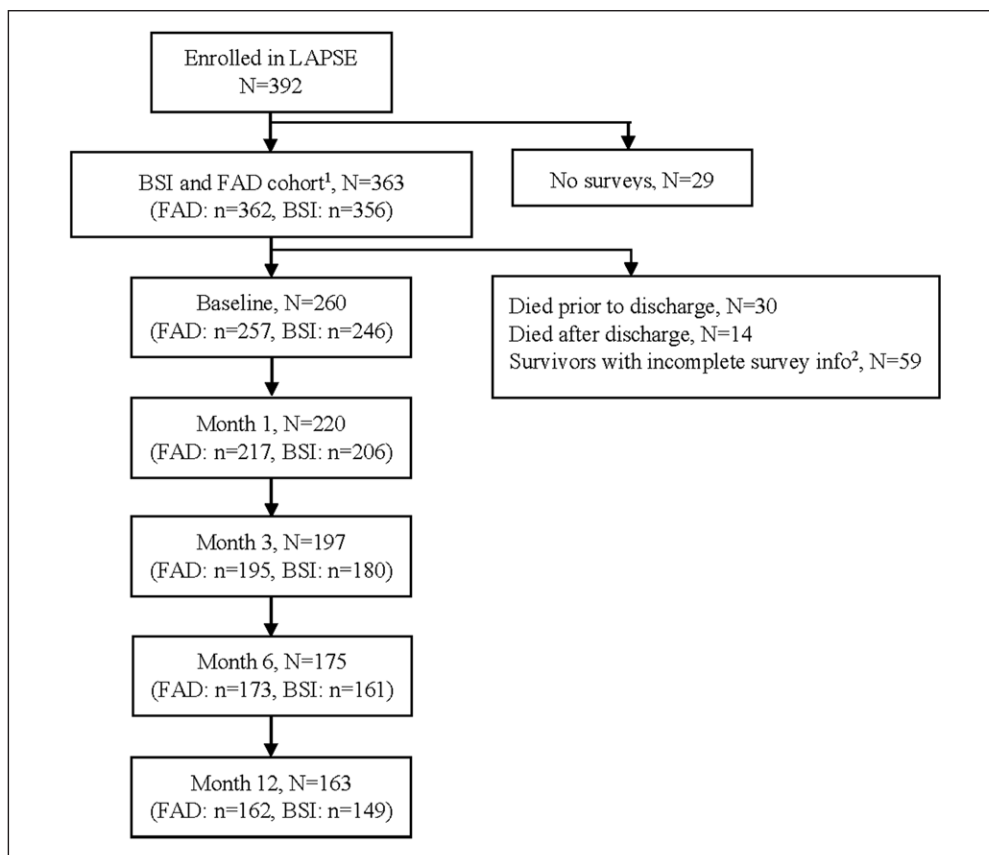
outcome study investigating child and family outcomes after community-acquired pediatric septic shock. Inclusion criteria were as follows: 1) age between 44-week gestation and 18 years old; 2) diagnosis of community-acquired infection or sepsis diagnosed within 48 hours of hospital admission; 3) systemic inflammatory response syndrome (at least two of four criteria, one must involve the patient's WBC count or the patient's body temperature); 4) cardiovascular organ dysfunction (requiring vasoactive-inotropic infusion); and 5) pulmonary organ dysfunction (requiring invasive or noninvasive positive-pressure ventilatory support). For this secondary analysis, only families of 12-month survivors of pediatric septic shock with a baseline and at least one completed follow-up survey were included. Exclusion criteria were as follows: 1) thermal or electrical burn as primary reason for admission; 2) lack of commitment to aggressive intensive care as indicated by do-not-resuscitate orders or other limitations; 3) caregivers unable to speak English or Spanish; 4) patient is in foster care; and 5) patient not enrolled within first 48 hours of PICU admission. This study was approved by the institutional review boards for each site; caregiver permission was obtained before patient participation and assent was obtained when developmentally appropriate for continued participation following PICU discharge. Children's primary caregivers were invited to participate, and 96% of the caregivers in this sample were biologic parents. For simplicity and accuracy, we use the word "caregiver" throughout the manuscript.

### Participant Flow

Of the 392 families enrolled in LAPSE, 260 families were included in this secondary analysis focusing on caregiver distress and family adjustment outcomes (Fig. 1). Twenty-nine families were excluded because they had not completed baseline Brief Symptom Inventory (BSI) or Family Assessment Device (FAD) surveys. Among the remaining 363 families, 30 had children who died before PICU discharge and an additional 14 had children who died after discharge. Fifty-nine families were excluded because they did not complete at least one follow-up assessment. In total, 163 of 260 (63%) completed both the baseline survey and the 12-month follow-up survey (162 completed the FAD and 149 completed the BSI).

### Measures

**Sociodemographics and Clinical Characteristics.** Research staff collected data related to family sociodemographics at the time of enrollment, as well as clinical characteristics both at the time of enrollment and during the PICU course. A Pediatric Risk of Mortality-III (PRISM-III with modified assessment window) (28) score was calculated at admission. Composite organ dysfunction was assessed daily using Pediatric Logistic Organ Dysfunction-2 scores (29). A Vasoactive-Inotropic Score (30) and mechanical ventilation (defined as invasive or non-invasive positive-pressure support, excluding high-flow nasal cannula) settings were recorded daily at 08:00 and 20:00. Other pathologic neurologic signs/events were recorded daily and included: anisocoria or absence of pupillary response, pathologic



**Figure 1.** Participant flow. <sup>1</sup>Participants who had at least one Brief Symptom Inventory (BSI) or Family Assessment Device (FAD). <sup>2</sup>Participants who did not have a baseline and one additional follow-up assessment. LAPSE = Life After Pediatric Sepsis Evaluation.

breathing pattern, stereotypic posturing or flaccid posture, seizure activity or abnormal electroencephalogram, new anoxic-ischemic injury on CT/MRI imaging, treatment for increased intracranial pressure, neurologic injury suspected by care provider, autonomic storming, and cardiopulmonary arrest or chest compressions. Chronic comorbid conditions were categorized using the Pediatric Medical Complexity Algorithm (31) for 3-year time period before and including admission. As such, immunocompromised patients (e.g., neutropenic oncology patients, transplant patients, and rheumatologic disorders) were included in the chronic comorbid conditions group.

**Family Functioning.** Caregivers completed the 12-item General Functioning scale of the FAD (32). Caregivers indicated how well each item described their own family on a four-point scale (1 = strongly agree; 4 = strongly disagree). Overall mean scores of two or higher indicate heightened stress and poor functioning. The FAD demonstrates adequate test-retest reliability and is considered a well-established measure of family functioning in pediatric samples (32–34).

**Caregiver Distress.** Caregivers' psychologic functioning was assessed with the BSI (35), an 18-item measure that assesses somatization, depression, anxiety, and panic symptoms. For the purposes of this study, and because real-time monitoring of survey responses was not possible across study sites, the item assessing suicidality was removed. Caregivers indicated how distressed they were by each problem during the past 7 days on

a five-point scale (0 = not at all; 4 = extremely). The BSI yields four subscales (somatization, depression, anxiety, and panic) and a summary overall scale, with higher scores indicating greater distress. The BSI has been administered in other pediatric acute illness samples (36). Clinical cut-off scores for BSI are greater than 10 for men and greater than 13 for women. Given that an item was removed and cut-off scores differ by sex, BSI total scores were reported descriptively.

### Statistical Analyses

Summary statistics are reported using counts and percentages for categorical variables and medians and interquartile ranges (IQRs) for continuous variables unless otherwise noted. Differences in variables measuring caregiver distress and family functioning are compared using the Wilcoxon rank-sum and likelihood ratio tests with medians and IQRs reported.

Repeated BSI and FAD measures collected at 1, 3, 6, and 12 months were analyzed using a group-based trajectory modeling approach as implemented in the SAS procedure “proc traj” (37). This procedure was used to identify trajectories, or patterns, of change in BSI and FAD over time by first fitting a basic one-trajectory group model to a quadratic polynomial equation. Trajectory plots modeling two, three, four, and five trajectory groups were examined for subsequent regression modeling. After weighing both clinical relevance and penalized fit for each candidate trajectory plot, the three-group trajectory model for BSI and the four-group trajectory model for FAD were chosen. Group membership probabilities were calculated for each subject with group membership being assigned to the group with the highest probability of membership.

Factors hypothesized to contribute to caregiver distress or family dysfunction were used to model high-risk BSI and FAD group membership probability. Univariable regression results include CIs based on a profile likelihood method and *p* values from the likelihood ratio test. Corresponding effect sizes (ESs) are also reported. A bidirectional stepwise selection procedure was used to build a multivariable model for the probability of BSI high-risk group membership for all variables. *P* value entry and exit upper thresholds for stepwise modeling were set at 0.20 and 0.10, respectively. All analyses were performed in SAS 9.4 (SAS Institute, Cary, NC).

**TABLE 1. Sociodemographic Characteristics of the Sample**

Characteristic	Overall, n (%)
Female	117 (45.0)
Age	
0–12 mo	40 (15.4)
13–24 mo	27 (10.4)
2–4 yr	44 (16.9)
5–7 yr	28 (10.8)
8–12 yr	54 (20.8)
13–17 yr	67 (25.8)
Race	
White	164 (68.0)
Black or African American	52 (21.6)
Other	25 (10.4)
Hispanic	50 (19.3)
Caregiver education level	
High school graduate, general educational development, or less	78 (30.5)
Vocational school, some college, or 2-yr degree	73 (28.5)
College degree	65 (25.4)
Graduate or doctoral degree	40 (15.6)
Annual household income	
<\$30,000	68 (30.0)
\$30,000 to <\$50,000	44 (19.4)
\$50,000–100,000	63 (27.8)
≥\$100,000	52 (22.9)
Single-parent household	85 (34.4)
Male	8/85 (9.4)
Female	77/85 (90.6)
Child insured through state Medicaid	134 (52.3)
Child resides at home with parent(s)	244 (94.9)
Biologic parent	250 (96.2)
Sex of caregiver: female	207 (80.5)

n = 260. The following variables had missingness for (x) subjects: race (19), ethnicity (1), parent education level (4), annual household income (33), parent marital status (13), child on Medicaid (4), child residence status (3), and sex of parent (3).

**RESULTS**

**Descriptives**

Baseline sociodemographic and clinical characteristics are depicted in **Tables 1** and **2**, respectively. The age breakdown of the children included 15.4% 0–12 months old, 27.3% 1–4 years old, 31.5%

**TABLE 2. Clinical Characteristics of the Sample**

Characteristic	Overall, n (%), Median (IQR)
Baseline	
Immunocompromised	49 (18.8)
Chronic comorbid conditions <sup>a</sup>	
None	118 (45.6)
Noncomplex	14 (5.4)
Complex	127 (49.0)
Nature of infection at the time of eligibility	
Documented	113 (43.5)
Suspected	147 (56.5)
Overall Pediatric Risk of Mortality score	11.0 (6.0–16.5)
Chronic device at baseline	137 (52.7)
On-study	
PRBC transfusion on-study	124 (47.7)
Total RBC transfusion (mL/kg) <sup>b</sup>	15.7 (11.5–32.8)
PICU length of stay (d)	9.1 (5.3–14.9)
No. of mechanical ventilator days	8.0 (4.0–12.0)
Sum of Pediatric Logistic Organ Dysfunction	51.0 (29.0–87.0)
Maximum Vasoactive-Inotropic Score during PICU stay <sup>c</sup>	
≤ 20	186 (71.5)
> 20	74 (28.5)
Neurologic insult(s) during PICU stay <sup>d</sup>	101 (38.8)
Extracorporeal membrane oxygenation during PICU stay	11 (4.2)
Renal replacement therapy during PICU stay	21 (8.1)
Cardiopulmonary arrest or chest compressions	11 (4.2)

IQR = interquartile range.

<sup>a</sup>Assessed using the Pediatric Medical Complexity Algorithm (31) for 3-year time period before admission.

<sup>b</sup>Calculated using only subjects who received a transfusion.

<sup>c</sup>Either before or after hospitalization.

<sup>d</sup>Inclusive of the following: anisocoria or absence of pupillary response, pathologic breathing pattern, stereotypic posturing or flaccid posture, seizure activity or abnormal electroencephalogram, new anoxic-ischemic injury on CT/MRI imaging, treatment for increased intracranial pressure, neurologic injury suspected by care provider, autonomic storming, cardiopulmonary arrest, or chest compressions.

n = 260. The following variable had missingness for (x) subjects: chronic comorbid conditions (1).

5–12 years old, and 25.8% 13–17 years old. The sample was predominantly Caucasian (68.0% white, 21.6% black, 10.4% other); 19.3% were Hispanic. The majority of caregiver participants were



**TABLE 3. Caregiver Distress and Family Functioning Over Time**

Measure	Time Point				
	Baseline	Month 1	Month 3	Month 6	Month 12
Caregiver distress measures					
No. of respondents	246	206	180	161	149
Somatization	3.3 (4.45)	2.0 (3.05)	1.8 (2.93)	1.5 (2.39)	1.7 (2.94)
		$p \leq 0.001^a$	$p \leq 0.001^a$	$p \leq 0.001^a$	$p \leq 0.001^a$
Depression	3.4 (3.83)	2.5 (3.29)	2.5 (3.67)	2.0 (2.93)	2.1 (3.10)
		$p \leq 0.001^a$	$p \leq 0.001^a$	$p \leq 0.001^a$	$p \leq 0.001^a$
Anxiety	3.7 (3.25)	2.4 (2.95)	2.1 (2.50)	1.8 (2.35)	2.2 (2.52)
		$p \leq 0.001^a$	$p \leq 0.001^a$	$p \leq 0.001^a$	$p \leq 0.001^a$
Panic	2.5 (3.09)	1.4 (2.35)	1.2 (2.07)	0.9 (1.63)	1.0 (1.92)
		$p \leq 0.001^a$	$p \leq 0.001^a$	$p \leq 0.001^a$	$p \leq 0.001^a$
Overall Brief Symptom Inventory score	12.9 (12.39)	8.3 (9.92)	7.6 (9.31)	6.2 (7.54)	7.0 (8.70)
		$p \leq 0.001^a$	$p \leq 0.001^a$	$p \leq 0.001^a$	$p \leq 0.001^a$
Family functioning					
No. of respondents	257	217	195	173	162
Overall Family Assessment Device score	1.6 (0.46)	1.6 (0.50)	1.6 (0.51)	1.6 (0.46)	1.6 (0.48)
		$p = 0.08116^a$	$p = 0.3562^a$	$p = 0.0399^a$	$p = 0.4108^a$
Stressed <sup>b</sup>	52 (20.2%)	52 (24.0%)	51 (26.2%)	40 (23.1%)	50 (30.9%)
		$p = 0.329^c$	$p = 0.138^c$	$p = 0.475^c$	$p = 0.014^c$

<sup>a</sup>Wilcoxon signed-rank test comparing time point to baseline.

<sup>b</sup>Stressed is defined as an FAD score of  $\geq 2$ .

<sup>c</sup>Likelihood ratio test comparing time point to baseline.

female (80.5%). Clinically, half of youth had complex, chronic comorbid conditions (49.0%). Overall median PRISM score was 11.0 and PICU length of stay was 9 days. Families who were lost to follow-up did not significantly differ from those who completed 12-month assessments on baseline FAD, baseline BSI, child sex, race, caregiver education level, insurance status, sex of caregiver, medical complexity, or PICU length of stay. They did differ on age ( $p = 0.042$ ) such that caregivers of older children were more likely to be lost to follow-up (median, 4.0 yr [IQR, 2.0–5.0] vs median, 5.0 yr [IQR, 3.0–6.0]).

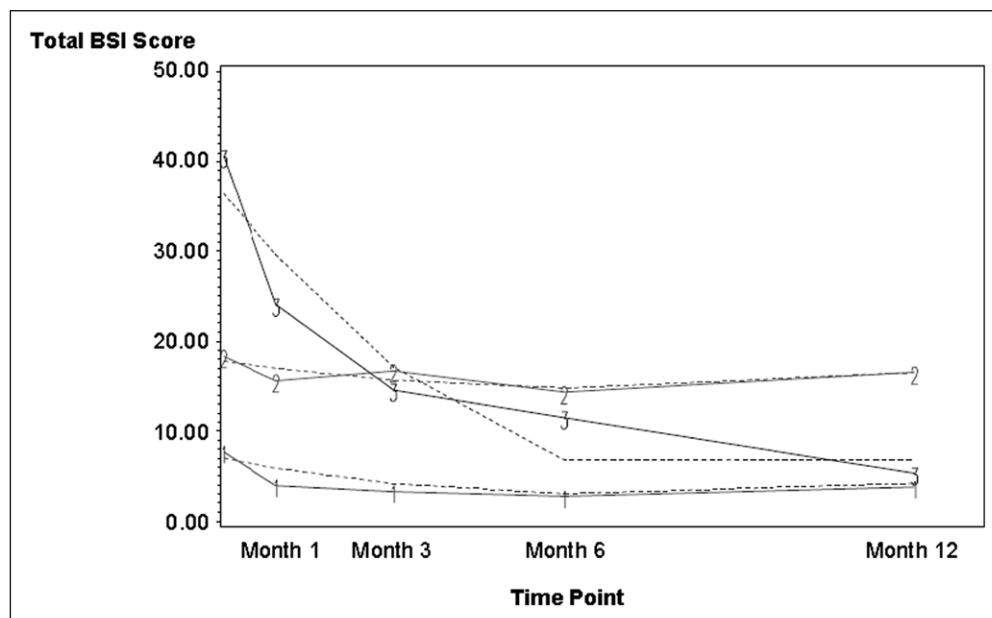
Regarding caregiver distress, mean overall BSI score decreased over time, from 12.9 (SD, 12.39) at baseline to 7.0 (SD, 8.70) at 12 months (Table 3). Regarding family functioning, mean FAD score for the full sample was 1.6 at each time point. However, the percentage of the sample with FAD of two or more (defined as “stressed and poor functioning”) increased significantly from 20.2% at baseline to 30.9% at 12-month follow-up ( $p = 0.014$ ).

### Caregiver Distress and Family Functioning Trajectories

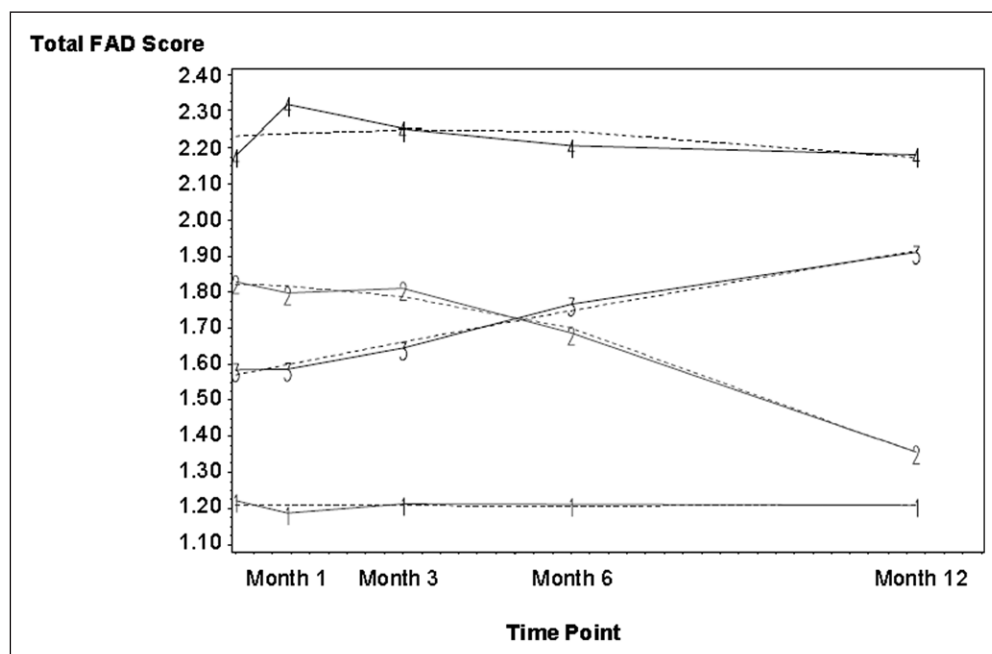
Group-based latent trajectory analyses were conducted to identify groups with similar distress and family functioning

trajectories. The parameter estimates and trajectories are depicted in Figs. 2 and 3. For caregiver distress, the largest group (group 1, 66.8% of the sample), labeled “Stable Low Distress,” was characterized by low, subclinical levels of distress at baseline that remained low across 12 months. The second group (group 2, 25.7% of the sample), labeled “Persistent Moderate-High Distress,” was characterized by moderate-high levels of distress at baseline that remained stable across 12 months. The third group (group 3, 7.6% of the sample), labeled “High Distress with Recovery,” was characterized by initial high levels of distress and gradual recovery. Specifically, this group demonstrated levels of distress similar to group 2 by 3-month follow-up, but returned to subclinical levels of distress by 12-month follow-up.

For family functioning, the largest group (group 1, 40.1% of the sample), labeled “Stable High Functioning,” was characterized by low levels of family dysfunction at baseline that remained low across 12 months. The second group (group 2, 12.3% of the sample), labeled “Improving Functioning,” was characterized by low-to-moderate levels of family dysfunction at baseline that decreased over 12 months to low levels of family dysfunction at follow-up. The third group (group 3, 32.3% of the sample), labeled “Deteriorating Functioning,” was characterized by low levels of family dysfunction at



**Figure 2.** Longitudinal trajectories of caregiver distress based on Brief Symptom Inventory (BSI) scores. Group 1 = stable low distress (66.8% of the sample); group 2 = persistent moderate-high distress (25.7% of the sample); group 3 = high distress with recovery (7.6% of the sample). The *solid line* depicts observed mean scores at each time point. The *dotted line* depicts the modeled estimates of trajectory over time. Clinical cut-offs for the BSI are greater than 10 for men and greater than 13 for women. Of note, one item on suicidality was removed from the BSI for the purpose of this study.



**Figure 3.** Longitudinal trajectories of family functioning based on Family Assessment Device (FAD) scores. Group 1 = stable high functioning (40.1% of the sample); group 2 = improving functioning (12.3% of the sample); group 3 = deteriorating functioning (32.3% of the sample); group 4 = persistent high dysfunction (15.3% of the sample). The *solid line* depicts observed mean scores at each time point. The *dotted line* depicts the modeled estimates of trajectory over time. Scores greater than 2 on the FAD indicate poor family functioning.

baseline that increased over 12 months such that at 12-month follow-up, the group approached the clinical cut-off for high family dysfunction. The fourth group (group 4, 15.3% of the sample), labeled “Persistent High Dysfunction,” was

characterized by clinically significant family dysfunction that persisted over 12 months. outcomes after pediatric critical illness have called for longitudinal studies of family functioning (9–12). To our knowledge, this is the first study to examine the course and factors associated with caregiver and family functioning after PICU admission for community-acquired septic shock. Families of

characterized by clinically significant family dysfunction that persisted over 12 months.

**Risk Factors Associated With Trajectory Group Membership**

In univariable analyses, both child age (age, 5–12 yr; ES, 0.14;  $p = 0.024$ ) and child race/ethnicity (non-white/Hispanic; ES,  $-0.12$ ;  $p = 0.008$ ) were significantly associated with BSI group 2 membership (high-risk BSI group) (Table 4). Specifically, caregivers of patients in middle childhood (age, 5–12 yr) had an estimated 0.14 increase in probability of high-risk group membership compared with caregivers of children in other age groups. Caregivers of patients who were non-white/Hispanic had an estimated 0.12 decrease in probability of high-risk group membership compared with caregivers of children who were white and non-Hispanic. In the final multivariate model that included both child age and race/ethnicity, only race/ethnicity continued to be a significant predictor of group membership (non-white/Hispanic; ES,  $-0.12$ ;  $p = 0.01$ ). There were no significant correlates of membership in FAD group 4 (high-risk FAD group) in univariable analyses and none met model entry criteria (sex,  $p = 0.299$ ). Multivariable analyses were, therefore, not conducted.

**DISCUSSION**

International Guidelines for Management of Sepsis and Septic Shock identify the promotion of family-centered care as a priority (8), and systematic reviews of psychosocial

**TABLE 4. Univariable Models Predicting Membership in High-Risk Groups**

Characteristic	Brief Symptom Inventory High-Risk Group <sup>a</sup> Probability		Family Assessment Device High-Risk Group <sup>a</sup> Probability	
	Effect (95% CI)	<i>p</i>	Effect (95% CI)	<i>p</i>
Sex		0.982		0.299
Male	Reference		Reference	
Female	0.00 (−0.09 to 0.09)		0.04 (−0.04 to 0.12)	
Age, yr		0.024		0.977
0–4	Reference		Reference	
5–12	0.14 (0.04–0.25)		−0.01 (−0.10 to 0.09)	
13–17	0.04 (−0.07 to 0.15)		0.00 (−0.09 to 0.10)	
Child's race/ethnicity		0.008		0.842
White, non-Hispanic	Reference		Reference	
Non-white/Hispanic	−0.12 (−0.21 to −0.03)		0.01 (−0.07 to 0.09)	
Chronic device use at baseline		0.883		0.824
No	Reference		Reference	
Yes	0.01 (−0.08 to 0.10)		0.01 (−0.07 to 0.09)	
Caregiver education level		0.968		0.719
High school graduate, general educational development, or less	Reference		Reference	
Vocational school, some college, or 2-yr degree	0.01 (−0.11 to 0.13)		0.01 (−0.09 to 0.11)	
College degree or beyond	−0.01 (−0.12 to 0.10)		−0.02 (−0.12 to 0.07)	
Annual household income		0.209		0.297
< \$30,000	0.05 (−0.08 to 0.18)		0.08 (−0.03 to 0.19)	
\$30,000 to < \$50,000	0.01 (−0.14 to 0.15)		0.00 (−0.12 to 0.12)	
\$50,000–100,000	Reference		Reference	
≥ \$100,000	0.14 (0.00–0.28)		0.08 (−0.03 to 0.19)	
Single-parent guardian		0.268		0.113
No	Reference		Reference	
Yes	−0.05 (−0.15 to 0.04)		0.07 (−0.02 to 0.15)	
Child insured through state Medicaid		0.744		0.932
No	Reference		Reference	
Yes	−0.02 (−0.11 to 0.08)		0.00 (−0.07 to 0.08)	
Sex of caregiver		0.175		0.914
Male	Reference		Reference	
Female	0.08 (−0.04 to 0.20)		0.01 (−0.09 to 0.11)	
Medical Complexity Algorithm Category		0.772		0.360
None/noncomplex	Reference		Reference	
Complex	0.01 (−0.08 to 0.10)		0.04 (−0.04 to 0.11)	
PICU length of stay (d)	−0.00 (−0.00 to 0.00)	0.522	−0.00 (−0.00 to 0.00)	0.942
Neurologic insult(s) during PICU stay <sup>b</sup>	0.04 (−0.05 to 0.14)	0.358	−0.04 (−0.12 to 0.04)	0.321

<sup>a</sup>Brief Symptom Inventory (BSI) and Family Assessment Device (FAD) high-risk group refers to BSI group 2 and FAD group 4 membership probabilities, respectively (refer to Figs. 2 and 3 for group trajectories over time).

<sup>b</sup>Inclusive of the following: anisocoria or absence of pupillary response, pathologic breathing pattern, stereotypic posturing or flaccid posture, seizure activity or abnormal electroencephalogram, new anoxic-ischemic injury on CT/MRI imaging, treatment for increased intracranial pressure, neurologic injury suspected by care provider, autonomic storming, cardiopulmonary arrest, or chest compressions

survivors were followed prospectively for 1 year. Although the majority of families demonstrated resilient trajectories after septic shock, as hypothesized, a subset of families demonstrated trajectories of persistently elevated distress and family dysfunction. Fully, 25.7% had moderate-high levels of distress at baseline that remained stable across 12 months, 32.3% had deteriorating family function over the 12 months, and 15.3% had persistently high family dysfunction throughout the 12 months.

A review of pediatric medical traumatic stress by Price et al (38) described four trajectories of caregiver responses: resilient (persistent low distress), recovery (initial high distress that decreases over time), and either chronic (high levels of distress that do not resolve over time) or escalating (distress that increases over time). Although the outcomes of the current study were instead focused more broadly on family functioning and general caregiver distress, the trajectories were nonetheless very similar. Findings are consistent with previous studies that have examined trajectories of caregiver distress after a range of pediatric medical events, such as pediatric cancer diagnosis and acute pediatric injury in the emergency department. This study extends previous findings by focusing on families of children in the PICU, which is the highest level of care in a hospital and often assumed to be the most distressing and potentially traumatic. This study also adds important information about trajectory of global family functioning. Furthermore, and consistent with previous reviews of family adjustment to pediatric illness (38, 39), the majority of caregivers and families in this sample demonstrated resilience during the 12 months after pediatric septic shock. Nonetheless, the subgroups that demonstrated chronic or escalating dysfunction and distress are important to identify as they may benefit from increased psychosocial support after discharge from the PICU (38).

Interestingly, mean levels of caregiver distress decreased over time from baseline to 12 months, whereas the percentage of families demonstrating significant family dysfunction increased over time. Furthermore, when examining family functioning, a fourth trajectory emerged that demonstrated deteriorating function over time, such that rates of family dysfunction were initially low at baseline but increased over 12 months. One possible explanation for these differences is that family function is a broader domain, and taps multiple systems that may each be impacted reciprocally over time by a child's acute medical event (e.g., the affected child, multiple caregivers, siblings). Whereas caregivers may exhibit heightened distress immediately after such events, greater family-level dysfunction may emerge well after discharge as the family continues to cope with issues related to their child's recovery (e.g., see Ref. [21]).

Contrary to hypotheses, no sociodemographic or clinical factors were significantly associated with membership in the high-risk family functioning group, and only child race/ethnicity was significantly associated with membership in the high-risk caregiver distress group in multivariate analysis. Specifically, caregivers of patients who were white had a significant increase in probability of high-risk group membership. This finding should be interpreted with caution, as multivariate

analyses compared youth who were white/Non-Hispanic to youth of all other races/ethnicities, and analyses were underpowered to examine racial and ethnic groups individually.

It is important to note that clinical factors did not significantly explain trajectories of caregiver distress and family dysfunction. Although clinical factors such as length of stay and medical severity are associated with poor psychosocial outcomes in youth following acute illness or injury (9, 40), caregiver and family outcomes after PICU admission have been examined less frequently. Results from this study are nonetheless consistent with two previous longitudinal studies that examined parental distress following pediatric hospitalization and found that medical factors (length of stay, predicted risk of mortality, diagnosis) are not significant predictors of parental posttraumatic stress (17, 22). Instead, these studies found that only premorbid psychosocial functioning (e.g., psychosocial care leading up to their child's illness, past stressful life events, mood symptoms) showed a significant relationship with parental symptoms over time. Therefore, current findings suggest that postdischarge support should not simply be focused on the families of the most severely ill patients but instead on those at highest risk. In addition, future studies examining caregiver and family functioning after pediatric septic shock should consider assessing premorbid domains of psychologic functioning, such as caregiver mental health history.

Strengths of this study include longitudinal assessment, multisite data collection, and broad assessment of caregiver distress and family functioning domains. This study also has several limitations. First, 59 families who did not complete at least one follow-up assessment were excluded and there was significant attrition by 12-month follow-up which may have influenced findings. However, this was similar to previous longitudinal studies of psychosocial outcomes after PICU hospitalization that also had significant attrition (e.g., see Refs. [17, 25]). There was also the potential for recall bias, as caregivers were asked to report on distress and functioning at baseline before the child's hospitalization. Of note, caregivers typically completed this assessment following stabilization of their child and were informed about the importance of the accuracy of this baseline assessment. Furthermore, although there was a clinical cut-off for the FAD, the BSI varies by sex of respondent and an item pertaining to suicidal ideation was removed for the purposes of this study. Although no single cut-off score could be applied, continuous symptom counts were nonetheless meaningful and used frequently in research examining caregiver distress after child illness (38).

Furthermore, although the focus of the current study was on baseline predictors of trajectories, it was also important to consider clinical characteristics that emerge after discharge. For example, new chronic device use and new neurologic disability should both be considered in future research. Finally, although participants were recruited from a range of pediatric hospitals that varied in geographic diversity, the current sample reflects a substantial proportion of families with incomes above \$100,000 and caregivers with doctoral/graduate degrees. This presents concerns regarding generalizability



for more under-resourced families. In addition, although we collected and examined caregiver demographics at baseline, it will also be important for future studies to consider factors such as income level, employment status, and marital status as outcomes themselves which may also be impacted by pediatric sepsis.

## CONCLUSIONS

Assessing caregiver and family functioning is an important part of family-centered care after community-acquired pediatric septic shock. Results from this study highlight that the majority of families of survivors of pediatric septic shock followed trajectories characterized by resilience. However, a subset of families demonstrated elevated distress and family dysfunction during the 1 year following PICU admission, and contrary to hypotheses, sociodemographic and clinical factors largely did not explain membership in these high-risk groups. This suggests that instead of directing resources for family psychosocial care based on the severity of child illness or family sociodemographic history, there may be need for continued family-based psychosocial screening after discharge. To optimize a child's recovery from critical illness, future studies may consider developing family-based psychosocial interventions for the subset of caregivers and families who continue to demonstrate distress and family dysfunction well after an event of pediatric septic shock.

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