Long-Term Function After Pediatric Critical Illness: Results From the Survivor Outcomes Study*

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Objective: Knowledge of the long-term outcomes of survivors of pediatric critical illness is sparse but important. The aim of this study was to evaluate morbidity and mortality 6 months and 3 years after hospital discharge.

Design: Prospective cohort study.

Setting: Urban, inner city, academic PICU.

Patients: Consecutive patients admitted to the PICU from June 2012 to August 2012.

Interventions: None.

Measurements and Main Results: We collected descriptive and demographic information and functional status assessments at baseline, admission, hospital discharge, 6 months and 3 years following discharge. Functional status was measured with the Functional Status Scale. New morbidity was defined as a change in Functional Status Scale score of greater than or equal to 3. Post-discharge assessments utilized scripted telephone surveys. Of 303 consecutive PICU patients, 253 were eligible and 129 parents consented. Follow-up outcomes were obtained for 77 patients (59.7%) at 6 months and 70 of these patients (54.2%) at 3 years. Both mortality and morbidity increased after discharge. Cumulative mortality increased from 3.9% ($n = 3$) at discharge to 7.8% ($n = 6$) at 6 months ($p = 0.08$) and 10.4% ($n = 8$) at 3 years ($p = 0.03$). New morbidity increased cumulatively from 5.2% ($n = 4$) at discharge to 6.5% ($n = 5$) at 6 months ($p = 0.65$) and 10.4% ($n = 8$) at 3 years ($p = 0.16$). Almost as many children demonstrated worsening of their functional status or died (38%) as children who survived without a change in functional status (44%). Less than 10% of children exhibited functional gains over time. Long-term functional outcome was associated with PICU variables including the need for invasive therapies and indicators of severity of illness such as use of mechanical ventilation, ventilator days, use of vasoactive medications, and PICU length of stay. The combined poor outcomes of new morbidity and mortality increased cumulatively from 9.1% ($n = 7$) at discharge to 14.3% ($n = 11$) at 6 months ($p = 0.16$) and 20.8% ($n = 16$) by 3 years ($p = 0.01$).

Conclusions: Mortality and new morbidity appear to substantially increase after discharge. Critical illness is associated with a sustained impact on survival and functional status. (*Pediatr Crit Care Med* 2017; 18:e122–e130)

Key Words: critical care outcomes; critical illness/mortality; intensive care units; morbidity; outcome assessment (health care)/methods; pediatric; survivors

***See also p. 292.**

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Mortality in the PICU has declined substantially due to a variety of factors including improved organization and delivery of care, medical and technologic advances, formalized physician training, and an improved understanding of pathophysiology (1–5). With the decline in mortality, there has been a concomitant increase in morbidity (5, 6). The number of children with moderate or severe long-term disability increased by 112% between 1982 and 2005–2006 in Australian children, and in the United States, the morbidity rate associated with critical care was recently estimated at 4.8%, twice the mortality rate (5, 6). The advent of improved survival has rendered mortality to be an insufficient metric of outcomes for many purposes (7). Better understanding of short-term and long-term outcomes and the factors associated with these outcomes is needed.

Long-term outcomes studies beyond 12 months post discharge are sparse, and no long-term functional outcomes

studies focusing on the general PICU population have been published in the last decade (8–15). Historically, studies of long-term PICU outcomes have been varied with regard to the population studied, the outcomes studied, the assessment methods used, and the duration of follow-up (12–23). Similarly, the limited number of studies of children admitted in 2006 or later have focused on specific groups such as long-stay patients or the chronic critically ill population, health-related quality of life (HRQOL), or other outcomes with only 1- to 6-month follow-up (24–28). The heterogeneity of outcomes examined (functional status, HRQOL, neurodevelopmental measures, etc.), the focus on specific populations (e.g., preterm infants), and the variable duration of long-term follow-up impair our understanding of long-term outcomes (8, 29, 30).

Characterizing short-term and long-term functional outcomes and identifying the factors that are associated with these outcomes could have an important translational impact on improving care. The objective of this study was to evaluate morbidity and mortality 6 months and 3 years after hospital discharge and determine which factors present at discharge were associated with these outcomes in a cohort of consecutive PICU admissions.

MATERIALS AND METHODS

Patients

Children were enrolled during a 13-week period between June 2012 and August 2012 in the PICU of The University of Chicago Comer Children's Hospital, an urban, academic, tertiary care center that admits medical and surgical pediatric patients. Patients were eligible for inclusion if they were under 18 years old, and it was their first PICU admission during the study period. Exclusions included children who were in the legal custody of the state and lack of English fluency because the follow-up assessment was conducted in English only. The institutional review board approved the study protocol, and informed consent was obtained from the parents/guardians.

Data and Outcomes

We reviewed the electronic medical record to collect demographic data, diagnosis, severity of illness, organ dysfunction, and length of stay (LOS). Primary diagnoses were broadly categorized as cardiovascular, neurologic, respiratory, and other (gastrointestinal, genitourinary, hematologic/oncologic, musculoskeletal, endocrinologic diseases, and trauma) due to sample size. To quantify functional status, we utilized the Functional Status Scale (FSS), an assessment method developed and validated by the Collaborative Pediatric Critical Care Research Network (CPCCRN) (6, 22). Functional status prior to admission (baseline), at PICU admission, and at hospital discharge was determined from the medical record. Baseline (pre illness) and PICU admission FSS may be different for some patients due to the illness precipitating PICU admission. We utilized baseline FSS in order to provide a global measure of comorbidity and admission FSS to provide a global measure of severity of illness. The FSS is amenable to follow-up studies of this nature due to ease of administration, its granularity, and objectivity of assessment compared with other available methods and has been used in other outcome studies including over 10,000 patients among the CPCCRN in the Trichotomous Outcomes In Pediatric Critical Care (TOPICC) study (6, 23). The FSS includes six domains: mental status, sensory, communication, motor function, feeding, and respiratory. Scores for each domain range from 1 (normal) to 5 (very severe dysfunction) with total scores ranging from 6 to 30. FSS scores were categorized according to previously described ranges (6, 23) that correspond to the Pediatric Overall Performance Category (POPC) groups: good: FSS 6–7, mildly abnormal: FSS 8–9, moderately abnormal: FSS 10–15, severely abnormal: FSS 16–21, and very severely abnormal: FSS greater than 21. Due to sample size, we grouped severely abnormal and very severely abnormal into a combined category of severe/very severe.

Morbidity and mortality were determined from the electronic medical record analogous to the TOPICC study by one trained member of the study team and telephone follow-up at 6 months and 3 years using a standardized telephone script by three trained members of the study team (23) (**Supplemental Fig. 1**: Telephone Script, Supplemental Digital Content 1, http://links.lww.com/PCC/A368). Three to five attempts to call each family were made. Parents were asked about their child's condition, including whether she/he was still alive and questions regarding morbidity. We defined new functional status morbidity by a worsening of FSS of 3 or greater from baseline to follow-up (6). Patients who died prior to the 3-year follow-up were classified as deaths, but the 6-month follow-up was included if they were alive at that time. We characterized patients who had acquired new morbidity or who had died by 3-year follow-up as "poor 3-year outcomes" and those who survived without new morbidity as "good 3-year outcomes."

We chose the follow-up intervals a priori to understand short-term outcomes (6 mo) and long-term outcomes (3 yr) to examine whether there would be substantial functional recovery or deterioration over time. These two time points were chosen to both reflect these outcomes and minimize the psychosocial issues following critical illness (7). Studies of survivors of pediatric critical injury suggest that the 6-month time point may represent a plateau in recovery and that the 3-year time point may represent a period of increased family dysfunction and stress (31–33).

Statistical Analysis

Demographics were summarized using median and interquartile range (IQR). Groups were compared using Wilcoxon rank-sum tests for continuous variables and chi-square/Fisher exact tests for categorical variables. FSS scores across all time points were compared using one-way repeated-measures analysis of variance. McNemar test for paired proportions compared the rates of mortality, new morbidity, and new mortality/morbidity over time. Univariate linear regression was performed to identify patient factors associated with FSS scores at 6 months and 3 years after discharge. We identified factors associated with poor 3-year outcomes utilizing logistic regression analysis. All analyses were performed with STATA version 14.0 (StataCorp LP, College Station, TX).

RESULTS

Sample Characteristics

During the enrollment period, 253 of 303 patients were eligible (**Fig. 1**). Parents of 129 patients consented to be part of the study (50.9%). Of these patients, 77 were available by telephone for initial functional outcome evaluation at 6 months (59.6%); this constituted the Survivor Outcomes Study cohort. The 52 patients lost to follow-up did not differ significantly from the study cohort with regard to age, gender, race, diagnosis category, percentage of surgical patients, use of mechanical ventilation, number of ventilator days, use of vasoactive medications, or PICU LOS. There were small differences in FSS scores at baseline and discharge between the lost to follow-up group and the study cohort (**Supplemental Table 1**: Patient Characteristics, Supplemental Digital Content 2, http://links.lww.com/PCC/A369). We obtained 3-year follow-up for 70 of these follow-up patients (90.9% of the 6-month cohort and 54.2% of all consented patients), including deaths.

Baseline characteristics of the cohort are presented in **Table 1**. The median age was 8.6 years (range, 0–18 yr). The cohort was balanced by gender, and the racial distribution (53.3% African American) reflected the PICU population. The 32 surgical patients comprised 41.6% of the cohort. Regarding ICU therapies, 21 patients (27.3%) received mechanical ventilation and seven patients (9.1%) received vasoactive medications. Median LOS in the PICU was 2 days (IQR, 1–7 d). Hospital mortality before discharge was 3 of 129 (2.3%) for all consented patients and 3 of 77 (3.9%) for the study cohort, consistent with institutional trends and rates generally found in multisite studies (6, 23).

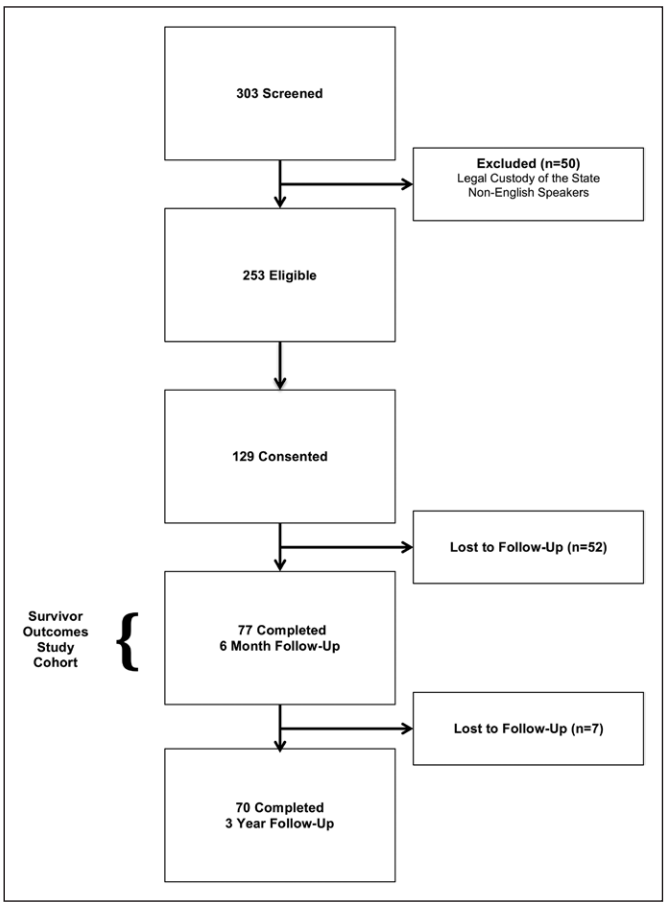

Figure 1. Enrollment

Outcomes

Both mortality and morbidity increased after discharge. There was a rise in cumulative mortality from 3.9% ($n = 3$) at discharge to 7.8% ($n = 6$) at 6 months ($p = 0.08$) and 10.4% ($n = 8$) at 3 years ($p = 0.03$) (**Fig. 2**). New morbidity increased cumulatively from 5.2% ($n = 4$) at discharge to 6.5% ($n = 5$) at 6 months ($p = 0.65$) and 10.4% ($n = 8$) at 3 years ($p = 0.16$). The combined poor outcomes of new morbidity and mortality increased cumulatively from 9.1% ($n = 7$) to 14.3% ($n = 11$) at 6 months ($p = 0.16$) and 20.8% ($n = 16$) by 3 years ($p = 0.01$). Among the eight children who died, the underlying causes of death were cancer ($n = 4$), chronic renal failure ($n = 1$), congenital heart disease ($n = 1$), hypoxic ischemic encephalopathy ($n = 1$), and ventriculoperitoneal shunt malfunction ($n = 1$).

Patients with poor 3-year outcomes were more likely to require mechanical ventilation (12 [75%] vs 7 [13%]; $p < 0.001$), a longer duration of mechanical ventilation (median duration, 4.0 vs 0 d; $p < 0.001$), treatment with vasoactive medications (5 [31.3%] vs 2 [3.7%]; $p = 0.006$), and have a longer length of PICU stay (median duration, 19.0 vs 2.0 d; $p < 0.0001$). Patients with poor 3-year outcomes and patients with good 3-year outcomes did not differ with regard to age, gender, race, or diagnosis (all comparisons, $p > 0.05$).

For those who survived with poor 3-year outcomes and for those who died by 3 years, their FSS was consistently worse than those who survived with good 3-year outcomes at baseline (8.7 vs 7.0, $p = 0.04$), admission (11.9 vs 8.0, $p = 0.0003$), hospital discharge (11.5 vs 7.2; $p < 0.0001$), and at 6-month follow-up (10.7 vs 7.2; $p < 0.0001$). (**Table 2**) The difference in scores at each time point was also greater than the difference that was present at baseline between these groups. The change in FSS scores for all time points was greater for those with poor outcomes than for those with good outcomes (all comparisons, $p < 0.0001$).

Trajectories

The percentage of survivors who exhibited good functional status decreased from 76.6% at baseline to 49.4% at admission (**Fig. 3*A***). Patients demonstrated partial recovery from their admission status with good functional status observed in 62.3% by discharge, 63.6% at 6 months, and 58.4% at 3-year follow-up. A total of 29 patients (37.7%) had a worsening of their FSS from baseline to 3 years, including the eight patients (10.4%) who died, whereas only seven (9%) improved and 34 (44.1%) had no change in FSS during that time period (**Fig. 3*B***). The patients who had worsening of their FSS over time experienced longer median LOS (8.0 vs 1.0 d; $p = 0.0001$) and were more likely to require mechanical ventilation (48.3 vs 12.2%; $p = 0.003$), but otherwise did not differ significantly from those who did not have a worsening of their FSS over

TABLE 1. Survivor Outcomes Study Cohort Characteristics

Variable	All Patients ($n = 77$)	Good 3-yr Outcomes ($n = 54$)	Poor 3-yr Outcomes[a] ($n = 16$)	p[b]
Age (yr), median (IQR)	8.60 (2.10–11.90)	9.90 (3.80–12.40)	2.85 (0.84–10.45)	0.08
Gender, *n* (%)				
Male	41 (53.3)	29 (53.7)	7 (43.8)	0.48
Female	36 (46.8)	25 (46.3)	9 (56.3)	
Race, *n* (%)				
African American/black	41 (53.3)	31 (60.8)	6 (37.5)	
White	22 (28.6)	13 (25.5)	8 (50.0)	0.18
Other	10 (13.0)	7 (13.7)	2 (12.5)	
Unknown	4 (5.2)	3 (5.6)	0	
Diagnosis, *n* (%)				
Cardiovascular	8 (10.4)	3 (5.6)	4 (25.0)	
Respiratory	20 (26.0)	14 (25.9)	4 (25)	0.11
Neurologic	23 (29.9)	15 (27.8)	5 (31.3)	
Other	26 (33.8)	22 (40.7)	3 (18.8)	
Surgical, *n* (%)	32 (41.6)	22(40.7)	7 (43.8)	0.83
Use of mechanical ventilation, *n* (%)	21 (27.3)	7 (13.0)	12 (75.0)	< 0.001
Ventilator days, median (IQR)	0.00 (0.00–1.00)	0.00 (0.00–0.00)	4.00 (0.50–17.00)	< 0.001
Use of vasoactive medications, *n* (%)	7 (9.1)	2 (3.7)	5 (31.3)	0.006
Use of closed chest cardiac massage, *n* (%)	2 (2.6)	0	1 (6.3)	0.23
PICU length of stay, d, median (IQR)	2.00 (1.00–7.00)	2.00 (1.00–3.00)	19.00 (7.00–43.50)	< 0.001

IQR = interquartile range.

[a]Poor 3-year outcomes were defined by a change in Functional Status Scale of 3 or more points or death.

[b]*p* for comparison between good 3-year outcomes and poor 3-year outcomes groups were calculated using Wilcoxon rank-sum tests for continuous variables and chi-square/Fisher exact tests for categorical variables.

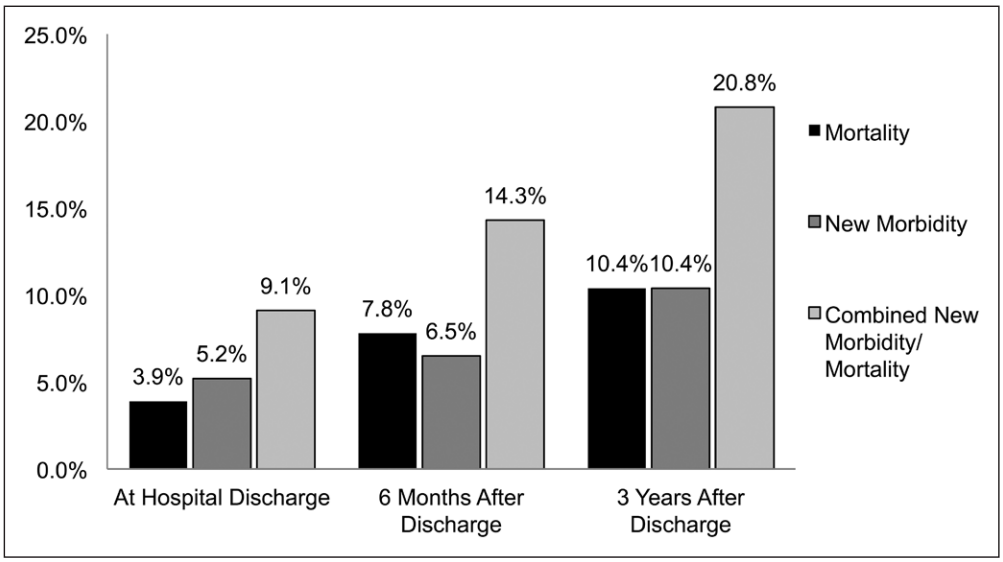

Figure 2. Cumulative mortality, new morbidity, and combined new morbidity/mortality in the survivor outcomes study cohort.

time. The individual patient trajectories revealed a general pattern: low FSS scores at baseline, peak dysfunction at admission, partial recovery at discharge, and minimal continued recovery at follow-up. Patients with poor 3-year outcomes exhibited wider fluctuations in their individual trajectories than patients with good 3-year outcomes (**Fig. 4, *A*** and ***B***).

Associations With Long-Term Outcomes

We examined the association of demographic and therapeutic variables (**Table 3**) with 6-month FSS, 3-year FSS, and

TABLE 2. Functional Status Scale Scores in the Survivor Outcomes Study Cohort

FSS/Change in FSS	Entire Cohort ($n = 77$)	Good 3-yr Outcomes ($n = 54$)	Poor 3-yr Outcomes ($n = 16$)	p[a]
Baseline FSS				
Mean (± SD)	7.3 (± 2.9)	7.0 (± 2.0)	8.7 (± 5.1)	0.04
Median (IQR)	6.0 (6.0 to 7.0)	6.0 (6.0 to 7.0)	7.0 (6.0 to 8.5)	
Admission FSS				
Mean (± SD)	8.8 (± 3.6)	8.0 (± 2.8)	11.9 (± 4.9)	< 0.001
Median (IQR)	8.0 (6.0 to 10.0)	7.0 (6.0 to 9.0)	10.0 (9.0 to 13.0)	
Discharge FSS[b]				
Mean (± SD)	7.8 (± 3.3)	7.2 (± 2.0)	11.5 (± 5.3)	< 0.001
Median (IQR)	6.0 (6.0 to 9.0)	6.0 (6.0 to 8.0)	10.0 (8.0 to 11.0)	
Six Month FSS[b]				
Mean (± SD)	7.6 (± 2.5)	7.2 (± 2.2)	10.7 (± 2.7)	< 0.001
Median (IQR)	6.0 (6.0 to 9.0)	6.0 (6.0 to 7.0)	10.5 (9.0 to 12.0)	
3-yr FSS[b]				
Mean (± SD)	7.5 (± 2.3)	7.0 (± 1.8)	11.4 (± 1.9)	< 0.001
Median (IQR)	6.0 (6.0 to 8.0)	6.0 (6.0 to 7.0)	11.0 (10.0 to 13.0)	
Change from baseline to discharge FSS[b]				
Mean (± SD)	+0.5 (± 1.7)	+0.2 (± 0.7)	+3.4 (± 3.7)	< 0.001
Median (IQR)	0.0 (0.0 to 0.0)	0.0 (0.0 to 0.0)	+2.0 (2.0 to 3.5)	
Change from baseline to 6-mo FSS[b]				
Mean (± SD)	+0.6 (± 1.8)	+0.2 (± 0.9)	+3.1 (± 2.5)	< 0.001
Median (IQR)	0.0 (−1.0 to 0.0)	0.0 to 0.0)	+2.0 (2.0 to 3.5)	
Change from baseline to 3-yr FSS[b]				
Mean (± SD)	+0.5 (± 1.8)	0.0 (± 1.2)	+3.9 (± 1.7)	< 0.001
Median (IQR)	0.0 (−1.0 to 0.0)	0.0 (0.0 to 0.0)	+3.0 (3.0 to 4.0)	

FSS = Functional Status Scale, IQR = interquartile range.
[a]p for comparison between good 3-year outcomes and poor 3-year outcomes groups were calculated using Wilcoxon rank-sum tests.
[b]Excluded patients who died.

poor 3-year outcomes. In univariate analyses, increased 3-year FSS scores were associated with increased ventilator days, increased LOS, increased baseline FSS, increased admission FSS, increased discharge FSS, and increased 6-month FSS. Age, race, and a surgical diagnosis were not associated with 3-year FSS. We found similar results for associations with the 6-month FSS. Similar results were found for outcome categories.

DISCUSSION

Our data provide objective information on the long-term functional status outcomes of patients undergoing contemporary PICU care. Cumulative mortality more than doubled 3 years after hospital discharge. New functional status morbidity was 33% higher than mortality at hospital discharge and doubled in 3 years. Cumulative morbidity and its change utilized a stringent definition of morbidity that incorporated only very significant new functional morbidity (6, 23, 34). The recommended increase of FSS of 3 or more was designed to ensure that the functional status morbidity would be very notable; 95% of children with an increase of 3 in the FSS had an increase of at least 2 in a single domain, which would be very notable to parents and physicians (6). Our finding of a cumulative increase in the combined outcome of new morbidity and mortality at 3 years is evidence of the medical vulnerability of children who survive critical illness. Almost as many children demonstrated worsening of their functional status or died ($n = 29$, 38%) as children who survived without a change in functional status ($n = 34$, 44%). Less than 10% of children ($n = 7$) exhibited functional gains over time. Poor long-term functional outcome was associated with invasive therapies and indicators of severity of illness including the use of

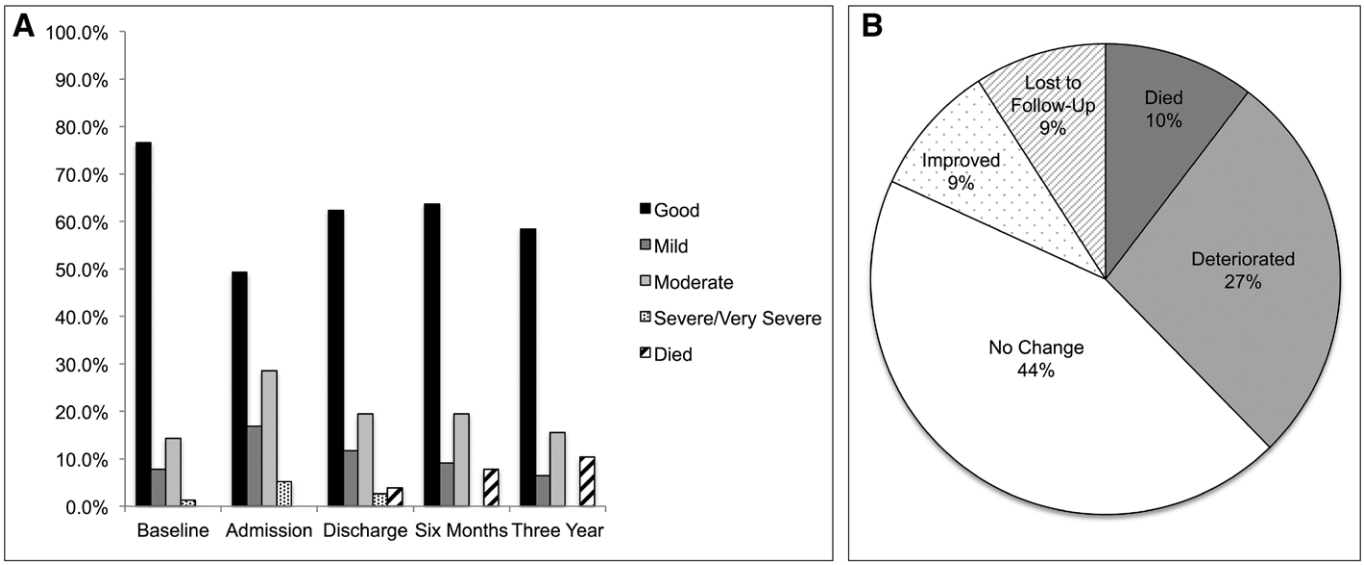

Figure 3. A, Functional Status Scale categories among the survivor outcomes study cohort. Patients exhibited peak dysfunction at admission, partial recovery at discharge, and minimal continued recovery at follow-up. **B**, Individual change in Functional Status Scale from baseline to 3-yr follow-up. Twenty-nine children (37.7%) had a worsening of their Functional Status Scale, including the 8 (10.4%) who died, whereas 7 (9%) improved between baseline and 3 years after hospital discharge. 34 (44.1%) of children had no change in Functional Status Scale in this time frame.

mechanical ventilation, number of ventilator days, use of vasoactive medications, and PICU LOS.

Assessing morbidity at discharge alone may underestimate the consequences associated with critical illness. The postdischarge increase in new, significant morbidity and mortality may be secondary to new morbidities that become evident after discharge, and/or progression of conditions present prior to admission or acquired during the illness. Surprisingly, few children improved over the 3 years. The overall prevalence of poor long-term outcomes may also be dependent on access to rehabilitative and support services, compliance with medical regimens, social support, coordination of care, new or repeat illness, and/or other comorbidities (8).

The data in this study are consistent with the increasing trend toward compromised outcomes from critical care, perhaps associated with increased survival. For example, 89.7% of pediatric critical care survivors admitted in 1995 had a favorable outcome with a likelihood of living independently and 83.6% had a favorable QOL at approximately 3.5 years after discharge as measured by the Health Utilities Index 1 (8). Jones et al (18) report more concerning results with only 27.3% of children admitted in 2001–2002 having full health at 6 months after admission as assessed by the Health Utilities Index 2. Similarly, 69% children admitted between 2002 and 2005 had physical sequelae 3 months after discharge as measured by the Pediatric Cerebral Performance Category (PCPC) and POPC (17). Using the Modified Glasgow Outcome Scale (MGOS), Namachivayam et al (5) found that 17.9% of children admitted in 2005–2006 had moderate or severe disability at approximately 1 year after discharge and for those with long-stays, 67% had unfavorable outcomes with 50% having died, and 17% having moderate or severe disability (24). Our study reflects similar results for a broader PICU population. However, comparison of previous studies is limited by the use of different outcomes measures across these studies. The definition of morbidity of the FSS of 3 or more indicated very significant functional morbidity. This cut-point worked well in the analysis but future studies may use different definitions of functional morbidity. Using our FSS cutoff of an increase (worsening) of 3 points in the total score and death to define poor outcome successfully categorized those with clearly negative outcomes. A larger study would allow a more robust analysis of the different definitions of significant functional status change. Use of a more liberal definition of morbidity or a global measure with less precision may substantially alter our measured effect (8, 27, 30).

Our ability to obtain functional status assessments for 91% of our 6-month study cohort at the 3-year follow-up reflects the feasibility of this study design with a focused telephone interviews at two separate time intervals. With two time points, we were able to provide an estimate of longitudinal trajectory with regard to functional status. We achieved a high rate of follow-up due in part to multiple attempts to reach parents and guardians. Our telephone script allowed for efficiency of the interview while maintaining engagement of the parent or guardian. Parents and guardians expressed gratitude for the follow-up call, particularly at 6 months. To our knowledge, this is the first use of the FSS via telephone and with validation could represent a useful method for long-term follow-up studies. We acknowledge that numerous factors may influence the reliable acquisition of long-term results. For example, population mobility may make it difficult to follow a representative sample because of socioeconomic factors (5). Our own patient population reflects the low socioeconomic status in our surrounding community with approximately 66% of patients admitted to our PICU covered by public insurance. Families report difficulty with maintaining permanent housing and reliable telephone numbers due to financial barriers, challenging the ability to locate children for long-term follow-up. Thus, the trajectories of recovery and deterioration

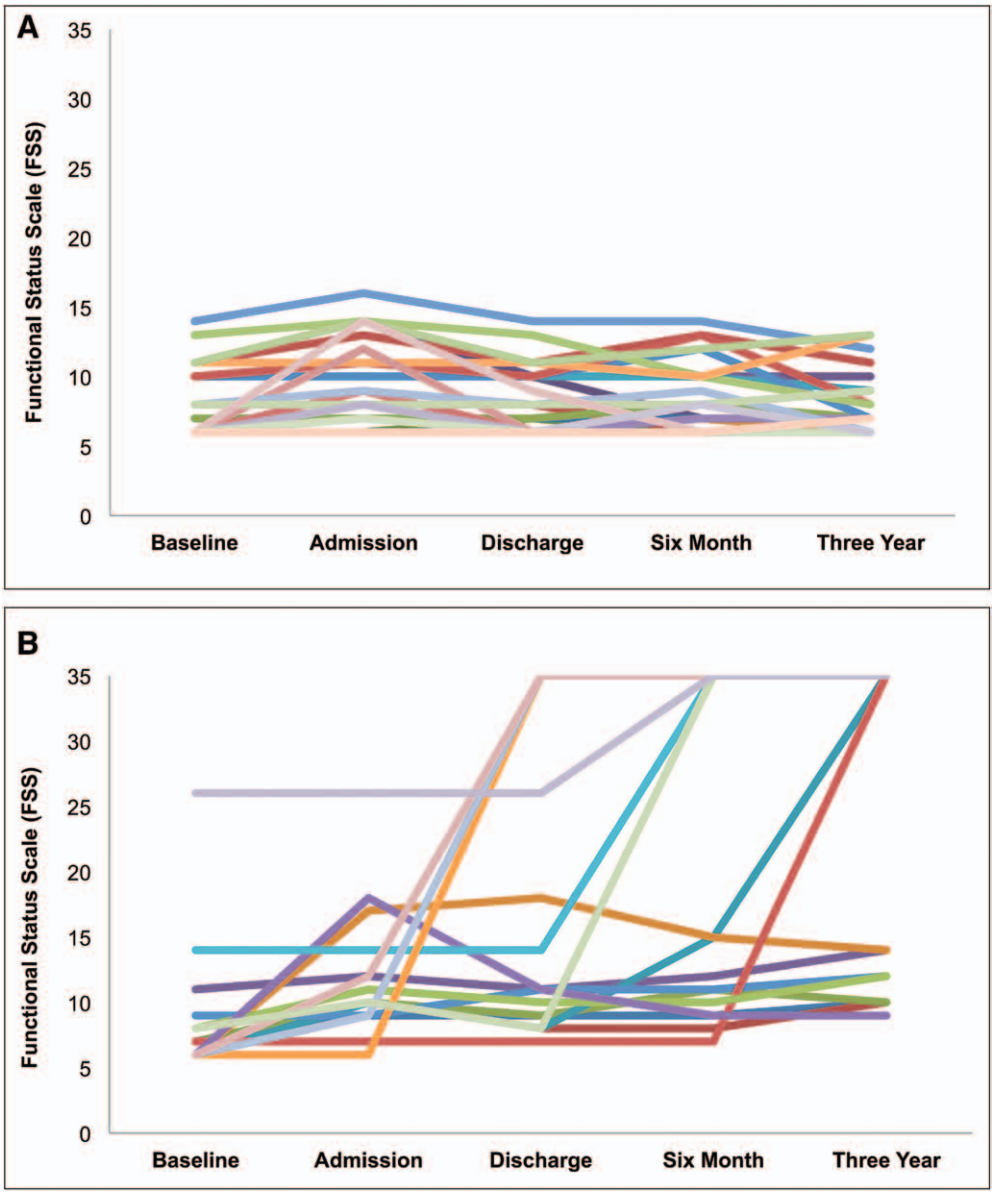

Figure 4. Trajectories of functional status of the (**A**) 54 patients with good 3-yr outcomes and (**B**) 16 patients with poor 3-yr outcomes. A change in less than 3 points in Functional Status Scale (FSS) scores from baseline to 3-yr follow-up was defined as good outcome, whereas a change of 3 or more points in FSS scores was defined as poor outcome. FSS scores ranged from 6-30. Death was represented by a score of 35.

may be influenced by the conditions of the population being followed, an issue that will need to be accounted for in future work.

Notably, the FSS is not a patient-reported outcome measure but does not require significant training of personnel, lengthy time for administration, or adaptation to growth and developmental norms (23, 30). Our assessment tool has the advantage of being easy to administer. FSS administration times in our study were 3–5 minutes, conferring an advantage over other functional, behavioral, cognitive, and HRQOL outcome measures (Vineland Adaptive Behavior Scale 2, Adaptive Behavior Assessment System 2, Pediatric Evaluation of Disability Inventory, Child Behavior Checklist, Bayley Scales of Infant Development, Weschler Intelligence Scales, Pediatric Quality of Life Inventory version 4.0), which necessitate longer administration times and may require trained personnel (30, 35, 36). Although the POPC, PCPC, MGOS, and Royal Alexandria Hospital for Children Measure of Function have similar ease and time of administration as the FSS, there may be greater interobserver variability with these scales (30). In a recent review of studies of functional outcome, the POPC and PCPC were the most widely used outcome measures (used in 44% of the studies reported, followed by the Health Utilities Index and MGOS) (30). The POPC, PCPC, and MGOS yield single summary scores; HRQOL measures may pose challenges for determining QOL in young patients with parents and children having different perceptions of HRQOL (30). Comparatively, the FSS provides increased granularity with its multidimensional assessment and objectivity in measurement (30, 34–36). We reported the FSS composite score in keeping with previous multisite studies and because our sample size precluded robust analysis of the six individual domains of the FSS (6, 23). Understanding which aspects of function are chronically most affected by pediatric critical illness may provide insight and direction for efforts to modify patient outcomes.

Our data highlight the need for a larger study in order to address the limitations of sample size, lack of more detailed data on comorbidities and severity of illness, and the potential effect of seasonality as our population was admitted during the summer. Notably, the change in FSS scores for all time points was greater for those who had poor outcomes than for those who had good outcomes, and this difference increased over time. Baseline differences in FSS may place children at differential risk of chronic and worsening changes in functional status, but other factors may also contribute to functional status changes. However, our sample size precluded further analysis of subgroups or severity of illness and restricted the regression analysis to univariate associations. A larger sample with more detailed baseline measures would allow us to elucidate whether these factors alone account for long-term outcomes. Multivariate analysis may improve our understanding of what factors are independently associated with long-term outcome

TABLE 3. Univariate Regression of Functional Status Scale at 6 Months, Functional Status Scale at 3 Years, and Poor 3-Year Outcomes in the Survivor Outcomes Study Cohort

	6-mo FSS		3-yr FSS		Poor 3-yr Outcomes[a]	
Variable	Coefficient (95% CI)	*p*	Coefficient (95% CI)	*p*	Odds Ratio (95% CI)	*p*
Age (yr)	−0.03 (−0.14 to 0.08)	0.59	−0.06 (−0.16 to 0.05)	0.28	0.91 (0.82–1.01)	0.08
Gender	0.98 (−0.20 to 2.15)	0.10	1.22 (0.09–2.37)	0.04	1.49 (0.49–4.59)	0.48
Race						
African American/ black	Reference	–	Reference	–	Reference	–
White	1.34 (−0.05 to 2.73)	0.06	1.06 (−0.32 to 2.44)	0.13	3.18 (0.92–11.00)	0.07
Other	0.62 (−1.24 to 2.48)	0.51	1.26 (−0.57 to 3.09)	0.17	1.48 (0.24– 8.91)	0.67
Diagnosis						
Cardiovascular	Reference	–	Reference		Reference	–
Respiratory	1.61 (−0.68 to 3.89)	0.17	0.56 (−1.90 to 3.03)	0.65	0.21 (0.03–1.38)	0.11
Neurologic	1.73 (−0.52 to 3.99)	0.13	1.68 (−0.74 to 4.11)	0.17	0.25 (0.04–1.52)	0.13
Other	0.25 (−1.98 to 2.48)	0.82	−0.35 (−2.74 to 2.04)	0.77	0.10 (0.01–0.70)	0.02
Surgical	−0.66 (−1.86 to 0.53)	0.27	−0.35 (−1.54 to 0.84)	0.56	1.13 (0.37–3.49)	0.83
Use of mechanical ventilation	1.42 (−0.01 to 2.84)	0.05	1.30 (−0.16 to 2.76)	0.08	20.14 (5.06–80.26)	<0.001
Ventilator days	0.09 (0.04–0.15)	0.001	0.08 (0.03–0.13)	0.003	1.44 (1.11–1.86)	<0.001
Use of vasoactive medications	1.54 (−1.03 to 4.10)	0.24	1.57 (−0.80 to 3.94)	0.19	11.82 (2.02–68.98)	0.006
Closed chest cardiac massage	−1.57 (−6.63 to 3.49)	0.54	–	–	–	–
PICU length of stay	0.07 (0.03–0.12)	0.001	0.07 (0.03–0.11)	0.0001	1.11 (1.04–1.18)	0.001
Baseline FSS	0.95 (0.73–1.18)	<0.001	0.77 (0.54–1.00)	0.0001	1.17 (0.97–1.42)	0.10
Admission FSS	0.54 (0.39–0.69)	<0.001	0.49 (0.35–0.63)	0.0001	1.33 (1.11–1.61)	0.002
Discharge FSS	0.89 (0.76–1.02)	<0.001	0.76 (0.62–0.89)	0.0001	1.58 (1.19–2.09)	0.002
6-mo FSS	–	–	0.79 (0.66–0.92)	0.0001	1.58 (1.21–2.07)	0.001

FSS = Functional Status Scale.

[a]Poor 3 Year Outcomes were defined by a change in Functional Status Scale of 3 or more points or death.

Dashes indicate not applicable.

and which factors are mitigated by other variables. Examining admissions throughout the year would also limit any seasonal variation in diagnoses that may have influenced our results. A larger sample may also allow analysis of the individual domains of the FSS, providing insight into whether certain aspects of function are more affected than others.

A second important limitation is generalizability. Our study single site cohort included all patients admitted to the PICU whose primary language was English and who were not in the legal custody of the state. Generalizability would have been improved by the inclusion of these groups. Although we were able to assess 3-year outcomes for 90.9% of the 6-month cohort, our overall follow-up rate was 54.2%. The study patients were a representative sample of our urban PICU with regard to age, race, gender, socioeconomic status, and admission diagnoses. The group lost to follow-up between hospital discharge and 6 months was reasonably similar to our study cohort. A sample from a more diverse population could have different results.

We believe intensivists should recognize improving long-term outcomes as a new challenge in addition to the traditional focus on outcomes at discharge (7). Nicholson et al (37) noted an "increasing need to undertake research that evaluates long-term outcomes after pediatric critical care." Our data suggest that including long-term outcomes is not only informative but also relevant and important to day-to-day decision making in the PICU.

CONCLUSIONS

The mortality rate more than doubled 3 years after hospital discharge. New morbidity was 33% higher than mortality at

hospital discharge and doubled in 3 years. Almost as many children demonstrated worsening of their functional status or died (38%) as children who survived without a change in functional status (44%). Less than 10% of children exhibited functional gains over time. Poor long-term functional outcome was associated with need for invasive therapies and indicators of severity of illness such as use of mechanical ventilation, ventilator days, use of vasoactive medications, and PICU LOS. This study is the first of its kind to use the more granular Functional Status Scale to follow patients after PICU discharge, providing evidence of its ease of administration via telephone interview.

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