Functional Recovery Following Critical Illness in Children: The "Wee-Cover" Pilot Study

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Dr. Choong was responsible for the study conception and design. Drs. Al-Harbi, Siu, Gorter, Khetani, Timmons, and Thabane contributed to the study methodology and interpretation of the data. Drs. Choong, Al- Harbi, and Siu were responsible for executing and coordinating the study and collecting study data. Ms. Wong was responsible for developing and managing the study database and data entry. Mr. Pogorzelski was responsible for managing the Participation and Environment Measure data collection and entry and interpretation of results. Dr. Choong, Mr. Cheng, and Dr. Thabane were responsible for statistical analyses. Dr. Choong drafted the article and every author contributed to revisions and approved the final version. The members of the Canadian Critical Care Trials group are responsible for mentoring this study through their provision of advice on the study methodology and design and review of the final article.

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Objective: To determine the feasibility of conducting a longitudinal prospective study to evaluate functional recovery and predictors of impaired functional recovery in critically ill children.

Design: Prospective pilot study.

Setting: Single-center PICU at McMaster Children's Hospital, Hamilton, Canada.

Patients: Children aged 12 months to 17 years, with at least one organ dysfunction, limited mobility or bed rest during the first 48 hours of PICU admission, and a minimum 48-hour PICU length of stay, were eligible. Patients transferred from a neonatal ICU prior to ever being discharged home, already mobilizing well or at baseline functional status at time of screening, with an English language barrier, and prior enrollment into this study, were excluded.

Interventions: None.

Measurements and Main Results: The primary outcome was feasibility, as defined by the ability to screen, enroll eligible patients, and execute the study procedures and measurements on participants. Secondary outcomes included functional status at baseline, 3 and 6 months, PICU morbidity, and mortality. Functional status was measured using the Pediatric Evaluation of Disability Inventory and the Participation and Environment Measure for Children and Youth. Thirty-three patients were enrolled between October 2012 and April 2013. Consent rate was 85%, and follow-up rates were 93% at 3 months and 71% at 6 months. We were able to execute the study procedures and measurements, demonstrating feasibility of conducting a future longitudinal study. Functional status deteriorated following critical illness. Recovery appears to be influenced by baseline health or functional status and severity of illness.

Conclusion: Longitudinal research is needed to understand how children recover after a critical illness. Our results suggest factors that may influence the recovery trajectory and were used to inform the methodology, outcomes of interest, and appropriate sample size of a larger multicenter study evaluating functional recovery in this population. (*Pediatr Crit Care Med* 2015; XX:00–00)

Key Words: critical illness; function; pediatrics; recovery

Increasing numbers of children require critical care annually because of a changing spectrum of pediatric disease, technological advancements, and improved survival

among extremely premature neonates and children with complex health conditions (1, 2). The overwhelming majority of children admitted to a PICU in developed countries survive their critical illness and return home to their families, schools, and communities (3). This decrease in mortality is unfortunately offset by the increase in morbidity among these children. Mortality is therefore no longer the ideal performance indicator for PICUs (4). In the last decade, PICU mortality rates have been cut in half, whereas children admitted with significant underlying chronic health conditions have "doubled," and PICU readmission rates have "tripled" (1, 5). Up to 67% of children admitted to PICUs today have a preexisting complex chronic health condition, and a significant proportion of these children also have abnormal baseline physical impairments (1, 6). These children are at risk of recurrent serious acute illnesses and PICU admissions (3), yet how children and their families recover after surviving a critical illness is poorly understood.

Evidence on the long-term sequelae of critical illness in children is extremely limited (7). We have yet to understand the recovery trajectories of these children, and whether they are similarly affected by the multitude of physical and neurocognitive critical illness sequelae observed in adults (8, 9), and the effect on their functioning at home, in school, and in community environments after hospital discharge. The overall objective of our research is to evaluate functional recovery and the predictors of functional recovery in critically ill children. Prior to a definitive study to achieve these objectives, we conducted a prospective pilot observational study to assess the feasibility of our methods and to inform the methodology of a future planned multicenter study.

METHODS

This prospective observational study was conducted at McMaster Children's Hospital, Hamilton, Canada, following institutional research ethics board approval. In order to enroll children at potential risk for the outcomes of interest and avoid "healthier" participants with short PICU stays, we considered the following: the patient should have 1) a minimum age (when one is expected to be gaining functional skills) and 2) a threshold severity of illness. Our inclusion criteria therefore consisted of age over 12 months to 17 years, presence of at least one organ dysfunction at admission (as measured by the Pediatric Logistic Organ Dysfunction score) (10), limited mobility or bed rest during the first 48 hours of PICU admission, a minimum 48-hour PICU length of stay, and informed consent or assent where appropriate. Children directly transferred from a neonatal ICU prior to ever being discharged home, those who were already mobilizing well or at baseline functional status at time of screening, patients and/or caregivers with an English language barrier, and prior enrolment into the study were excluded. We initially excluded patients with chronic neuromuscular disorders and acute spinal cord injuries; however, we subsequently removed this exclusion criterion in order to be inclusive in the context of a pilot and remain aligned with our original research question.

Outcome Measures

The primary outcome for this pilot study was feasibility, as defined by the ability to screen, consent, and enroll eligible patients and the ability to execute the study procedures and measurements on participants. Protocol violation, withdrawal, and follow-up rates were therefore assessed. Our secondary outcomes were selected based on anticipated clinically important endpoints for the definitive study, namely functional recovery over time. To measure functional status at baseline (i.e., prior to the critical illness) and 3 and 6 months following PICU discharge, we applied the International Classification of Functioning, Disability and Health–Version for Children and Youth (ICF-CY). The ICF-CY provides a framework to describe function in terms of what a child can do in a standard environment (capacity), as well as what the child does in his or her usual environment (capability, performance, and participation) (11). According to the ICF-CY, functioning is influenced by contextual factors, such as personal (i.e., age, gender, and caregiver characteristics) and environmental factors (i.e., physical, social, attitudinal, institutional supports and barriers) (12). We therefore measured functional outcomes in this study using a combination of validated instruments: 1) the Pediatric Evaluation of Disability Inventory (PEDI) to assess functional capabilities and task performance and 2) the Participation and Environment Measure (PEM) to assess participation and the environmental factors influencing participation. The PEDI is a standardized, parent-report assessment instrument designed to measure functional capabilities and performance in mobility and self-care tasks in children who are 6 months to 7.5 years old (13). Capability is measured via the Functional Skills Scale (FSS) (i.e., what a child can do in his/her daily environment) and performance is measured by the Caregiver Assistance Scale (CAS) (i.e., level of caregiver assistance needed to accomplish the same activities of the FSS). The PEM captures caregivers' perspectives of their child's participation in activities within the home, school, and community and environmental influences on participation for each setting (14). The PEM for Children and Youth was used for children who are 5–17 years old and Young Children's version was used for children who are below 5 years (15); hereafter, these measures are collectively referred to as "PEM." We offered caregivers the option of self-administering these surveys or completing them via interview, to optimize our follow-up response rates. Parental or caregiver stress is a contextual influence of a child's function and was measured using the Parental Stress Index (PSI) at 3 months post PICU discharge (16). We also measured functional capacities using Pediatric Overall Performance Category (POPC) and Pediatric Cerebral Performance Category (PCPC) scores as these are typical tools used to indicate overall cognitive and functional status at PICU admission and discharge (17). For purposes of comparison, we defined cognitive or functional limitation by a POPC or PCPC score of greater than 1 (18).

Clinical secondary outcomes included ventilator-free days, mortality, length of PICU and hospital stay, and morbidities attributable to prolonged immobility, such as new-onset joint contractures, pressure ulcers, and PICU-acquired weakness

(**Supplemental Appendix**, Supplemental Digital Content 1, http://links.lww.com/PCC/A147, for definitions and diagnostic criteria). Exercise tolerance was evaluated in an age-appropriate subgroup (> 4 yr) prior to hospital discharge and 3 and 6 months post-PICU discharge using the McMaster All-Out Progressive Continuous Cycling Test (19).

Statistical Analysis

As the sample size for this pilot was based on feasibility considerations, we planned to recruit at least 30 patients over 8 months. This sample size would also allow us to explore up to five potential predictors of functional recovery (our planned primary outcome for the definitive study), given a minimum of six patients per predictor variable. We planned to use these data to inform the sample size and methods of the larger multicenter study. Baseline participant characteristics were summarized using mean (SD) or median (Q1, Q3) depending on the distribution. The analysis of feasibility outcomes is descriptive and reported as estimates (95% CIs). Graphical summaries were used to display potential relationships between baseline characteristics and functional outcomes (PEDI and PEM). Regression analyses were exploratory and hypothesis generating in nature and for the purpose of informing the design of the larger multicenter study. As such, there was no adjustment for the overall level of significance for multiple testing. All the analyses were performed using STATA 13.0 (StataCorp LP, College Station, TX).

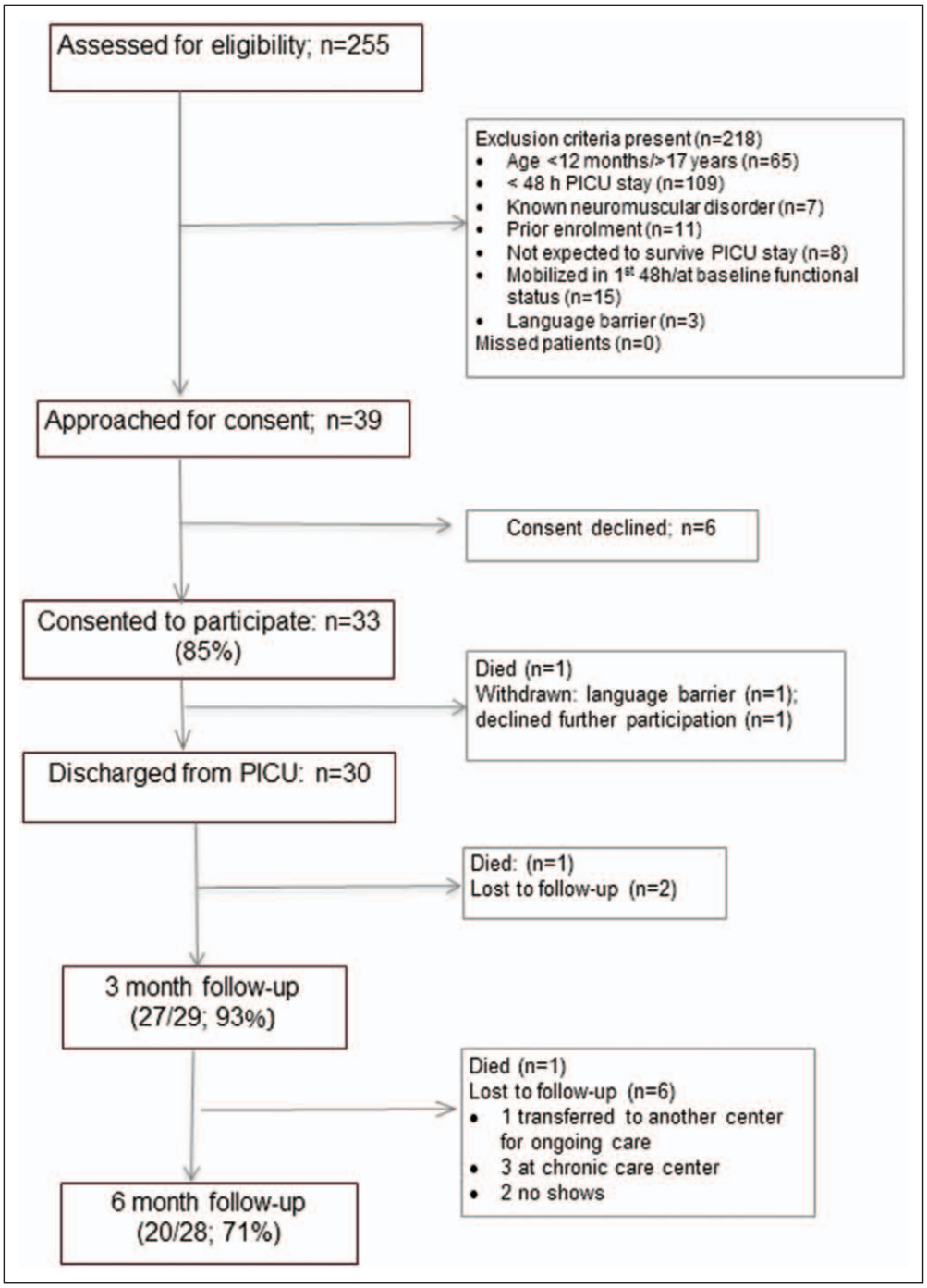

Figure 1. Participant enrollment and retention at follow-up.

RESULTS

Feasibility Outcomes

We completed enrollment between October 2012 and April 2013, 1 month earlier than anticipated. We screened 255 patients, 39 of whom were eligible and were approached and 33 were enrolled (85% consent rate) (**Fig. 1**). There were two withdrawals: one patient with a language barrier was inappropriately enrolled; in the second, the substitute decision makers withdrew consent to further participation prior to the patient's death. Baseline characteristics of the 33 enrolled patients are presented in **Table 1**. The mean (SD) age was 7.5 years (5.0), and 16 (48%) were male patients. The most frequent reason for PICU admission was respiratory failure (8/33; 24%). Sixteen of these patients (48%) had a preexisting comorbid chronic condition (defined as the presence a medical diagnosis for at least 6 mo). Fifteen of 33 children (45%) and 13 of 33 children (39%) had functional and cognitive limitations at baseline as determined by POPC and PCPC scores, respectively.

TABLE 1. Participant Characteristics at Baseline

Demographic Variables	No. of Patients (*n* = 33)
Age, yr; median (minimum, maximum); (Q1, Q3)	5.9 (1.2, 16.0); (3.4, 13.2)
Gender, male; *n* (%)	18 (55)
Primary reason for admission, *n* (%)	
Respiratory failure (including respiratory tract infection)	12 (36)
Sepsis	2 (6)
Shock	3 (9)
Trauma	4 (12)
Neurologic disorder	5 (15)
Elective postprocedure	3 (9)
Emergency surgery	3 (9)
Other	1 (3)
Preexisting comorbid chronic medical diagnosis, *n* (%)	16 (48)
Pediatric Risk of Mortality III score at admission, median (minimum, maximum); (Q1, Q3)	5 (0, 22); (2, 9)
Pediatric Logistic Organ Dysfunction score at admission, median (minimum, maximum); (Q1, Q3)	2 (0, 41); (1, 12)
Baseline PCPC score, median (Q1, Q3)	1 (1, 4)
Distribution of baseline PCPC scores, *n* (%)	
Normal (score of 1)	20 (61)
Mild disability (2)	2 (6)
Moderate disability (3)	2 (6)
Severe disability (4)	9 (27)
Coma or vegetative state (5)	0
POPC score, median (Q1, Q3)	1 (1, 4)
Distribution of baseline POPC scores, *n* (%)	
Good overall performance (score of 1)	18 (55)
Mild disability (2)	3 (9)
Moderate disability (3)	1 (3)
Severe disability (4)	11 (33)
Coma or vegetative state (5)	0

Q1 = the first quartile, Q3 = the third quartile, PCPC = Pediatric Cerebral Performance Category, POPC = Pediatric Overall Performance Category.
Range for POPC and PCPC scores is 1–7 (from 1 = normal, increasing scores indicating increasing disability, 6 = brain death, or 7 = cardiorespiratory death).

The follow-up rate of survivors was 27 of 29 (93%) at 3 months and 20 of 28 (71%) at 6 months (Fig. 1). Reported reasons for loss to follow-up from the total of eight participants were financial or transport limitations ($n = 2$), caregiver reports of being "overwhelmed" or "stressed" ($n = 7$), and because they were receiving ongoing care at another institution ($n = 4$). PSI at 3 months was a median percentile of 54 (range, 1–99) (normal range, 16–80; borderline, 81–84; clinically significant level of stress, ≥ 85 percentile) (20). Exercise testing was feasible in only two of 30 participants (6.7%). Reasons that exercise testing could not be conducted were young age ($n = 6$), cognitive or functional impairment ($n = 15$), physician preference ($n = 3$), patient refusal ($n = 2$), and parent refusal ($n = 2$).

Functional Outcomes

We observed that critical illness was associated with a deterioration in function in this study cohort, which appeared to improve over time, as measured by PEDI and POPC scores (**Table 2**). PEDI was able to further discriminate function according to premorbid condition in this population—PEDI scores in each domain were higher among previously healthy children than those with preexisting chronic conditions and baseline functional limitation (**Fig. 2**). Twenty-eight percent and 42% of the study cohort recovered to baseline function by 3 and 6 months, respectively, as measured by PEDI. However, only 22.2% of those with an preexisting chronic condition and 14.3% with functional limitations prior to their critical illness recovered to baseline by 6 months, compared with 60.0% in previously healthy children and 58.3% of children with normal baseline function (**Fig. 3**). **Table 3** presents the univariate analyses exploring predictors of functional deterioration and suggests that increasing severity of illness may be a predictor of a greater deterioration in function.

The PEM was completed via self-report in all but one of the 32 participants, who completed it by telephone interview at 3-month follow-up. Parents' perceptions of their child's participation in the home appeared to improve over time in the overall study cohort. However, our pilot data suggest that in comparison to previously healthy children, those with underlying baseline functional limitations participate less often in home-based activities at 3 and 6 months, particularly with nondiscretionary activities such as school preparation, personal care, and household chores (**Supplemental Fig. 1**, Supplemental Digital Content 2, http://links.lww.com/PCC/A148). At 6 months, 33% of parents of children with underlying functional limitation report environmental barriers to their child's participation at home, compared with 20% of parents of children with no baseline functional limitations, particularly with respect to the physical layout of the home, physical, and social demands of home-based activities, and services available in the home.

Clinical Outcomes

The secondary clinical outcomes of interest are outlined in **Table 4**. The overall mortality rate among the entire cohort who consented to participate was 9% (3/33). Two of the

TABLE 2. Functional Outcomes of Participants Over Time

Variable	Baseline (Premorbid)	3 Mo	6 Mo
Pediatric Evaluation of Disability Inventory score (scaled)[a]			
FSS Self-Care[b]	*n* = 28	*n* = 26	*n* = 20
Median (minimum, maximum); (Q1, Q3)	68.7 (21.4, 100); (40.4, 100)	59.55 (17.4, 100); (42, 85.1)	64.4 (33, 100); (39.95, 89.05)
FSS Mobility[b]	*n* = 28	*n* = 26	*n* =20
Median (minimum, maximum); (Q1, Q3)	74.5 (6.1, 100); (48.8, 100)	63.95 (18.20, 100); (44.3, 89.2)	70.1 (15.2,100); (54.35, 97.1)
CAS Self-Care[c]	*n* = 30	*n* = 27	*n* = 20
Median (minimum, maximum); (Q1, Q3)	67.45 (0, 100); (39.3, 100)	53.4 (0, 100); (35, 76.7)	65.7 (11.6, 100); (41.1, 100)
CAS Mobility[c]	*n* = 30	*n* = 27	*n* =20
Median (minimum, maximum); (Q1, Q3)	76.75 (0, 100); (40.9, 100)	58.8 (0, 100); (39, 100)	72.85 (0, 100); (51.05, 100)
Pediatric Overall Performance Category score	*n* = 30	*n* = 29	*n* = 28
Median (minimum, maximum); (Q1, Q3)	1 (1, 4); (1, 4)	2 (1, 4); (1, 4)	1 (1, 7); (1, 4)
Pediatric Cerebral Performance Category score	*n* = 30	*n* = 29	*n* = 28
Median (minimum, maximum); (Q1, Q3)	1 (1, 4); (1, 4)	3 (1, 4); (1, 4)	2 (1, 7); (1, 4)

FSS = Functional Skills Score, Q1 = the first quartile, Q3 = the third quartile, CAS = Caregiver Assistance Scales.

[a]Scaled scores are distributed along a continuum from 0 to 100, which represent relatively easy to relatively difficult items in a domain on the Pediatric Evaluation of Disability Inventory (PEDI). Increasing numbers indicate increasing degrees of functional performance of the child. Scaled scores can be used to describe children of all ages as it is not adjusted for age.

[b]FSS is self-administered. Two patients at baseline and one patient at 3 mo, respectively, did not complete this portion of the PEDI.

[c]CAS is administered by interview.

Range for Pediatric Overall Performance Category and Pediatric Cerebral Performance Category scores is 1–7 (from 1 = normal, increasing scores indicating increasing disability, 6 = brain death, or 7 = cardiorespiratory death). Data not available directly from the patients lost to follow-up were obtained from their medical records and/or by contact with their physician.

three patient deaths occurred after PICU discharge at 37 and 191 days, respectively. Nineteen patients (63%) required hospital readmission within 6 months of PICU discharge, eight of whom (42%) required PICU admission. The median number of readmissions to PICU in these patients was 1.5 (range, 0–3).

DISCUSSION

The emergence of important and persistent ICU-acquired functional and neurocognitive morbidities in adults has prompted significant growth of research focused on evaluating the role of early rehabilitation in the prevention and management of these sequelae (21). Although pediatric critical care is a rapidly evolving field, research in this area significantly lags behind that of adults and remains largely focused on immediate, short-term morbidity and mortality outcomes. Determining appropriate outcome measures in this population is complex, and measuring functional outcomes in critically ill children is challenging (22). The POPC and PCPC are brief, simple scores widely used in PICU literature that can provide useful information on patient outcomes (17). However, as there was no previously established gold standard, these scores were originally validated against indices of PICU morbidity (18). Function is not merely related to motor capacity, and hence, we felt that it was important that our selected outcome measures be aligned with emerging pediatric rehabilitation literature, suggesting a shift from the traditional focus on impairment and disability to understanding levels of functioning when performing tasks and participating in activities that children need and want to do as part of their everyday life (23). We therefore applied the ICF-CY framework by combining use of the PEDI and PEM, along with health outcomes and caregiver stress, as a more comprehensive and meaningful measure of functional outcome in this cohort of critically ill children. The PEDI is widely used in the clinical and research setting for assessing key functional capabilities and performance of discrete tasks and is sensitive to change (24). The PEM supplements the PEDI by enabling researchers to gain more insight into a child's functional capacity on home and community reintegration posthospital discharge (25). As parenting stress may contribute to poorer child health-related outcomes, it was important to include such a measurement (26). As this pilot study is the first to our knowledge to apply this paradigm of outcome measurement within a PICU setting, it was essential to demonstrate the feasibility of the methods and evaluate if the results justify a larger study.

This pilot study demonstrates that executing such a study design and outcome measurements are feasible in a single

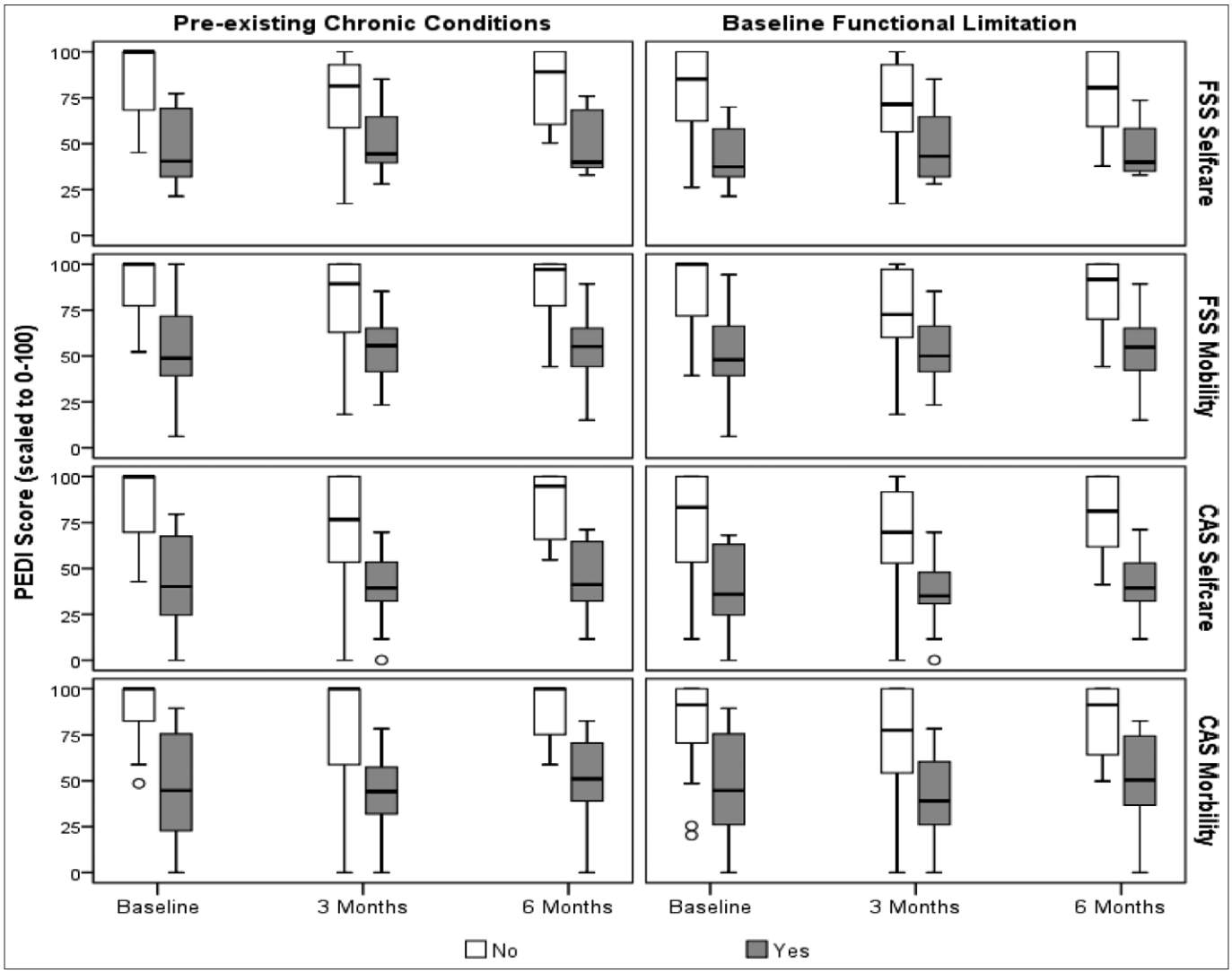

Figure 2. Functional status as measured by the Pediatric Evaluation of Disability Inventory (PEDI) score over time. The *boxplots* represent the median and interquartile range, whereas the *tails* indicate the minimum and maximum. PEDI (10) measures motor capability via the Functional Skills Scale (FSS) and motor performance via the Caregiver assistance scale (CAS), in the self-care and mobility domains, respectively. Scores are scaled 0–100, with a higher score indicating better function. Baseline functional limitation was defined as patients with a Pediatric Overall Performance Category score more than 1.

center. The consent rate was excellent, and patient recruitment was completed 1 month ahead of anticipated. The eligibility criteria were appropriate in selecting a cohort of patients who may be at risk of impaired functional recovery. Although the 3- and 6-month follow-up rates in this unfunded study are comparable to those observed in pediatric outpatient clinics and previous pediatric and adult longitudinal studies, they can be improved (27, 28). Reasons for loss to follow-up were multifactorial and most commonly attributable to psychosocial factors, such as access to transport, financial limitations, and parental self-reports of anxiety or depression. Our data are consistent with previous evidence suggesting that patients lost to follow-up may be systematically sicker (29, 30). Such information raises important concerns as to whether these patients are at greater risk of impaired functional recovery, highlights the need for further research in this area, and highlights the need to optimize a follow-up plan to capture such patients in future studies. Lessons learned from this pilot support the need to finance travel expenses for such families and budget for home-visits in the future study to ensure that the outcomes are not based on a potentially biased population. We evaluated the feasibility of including a measure of parental stress as this has been shown to influence functional and health-related outcomes in childhood illness (26, 31). However, we did not examine the relationship between parental stress scores, functional outcome, and critical illness severity, in the context of our small pilot sample size. Exercise testing was not feasible in this study cohort. Adult studies currently use tests of exercise capacity such as the 6-minute walk test, as a predictor of and to monitor physical function and recovery (32). We therefore chose to assess the feasibility of the gold standard exercise test in children with and without disabilities (33) and found that the vast majority of participants could not perform this test for reasons of young age and cognitive and functional limitations, thus questioning the utility of this test as a predictor of functional recovery in this population.

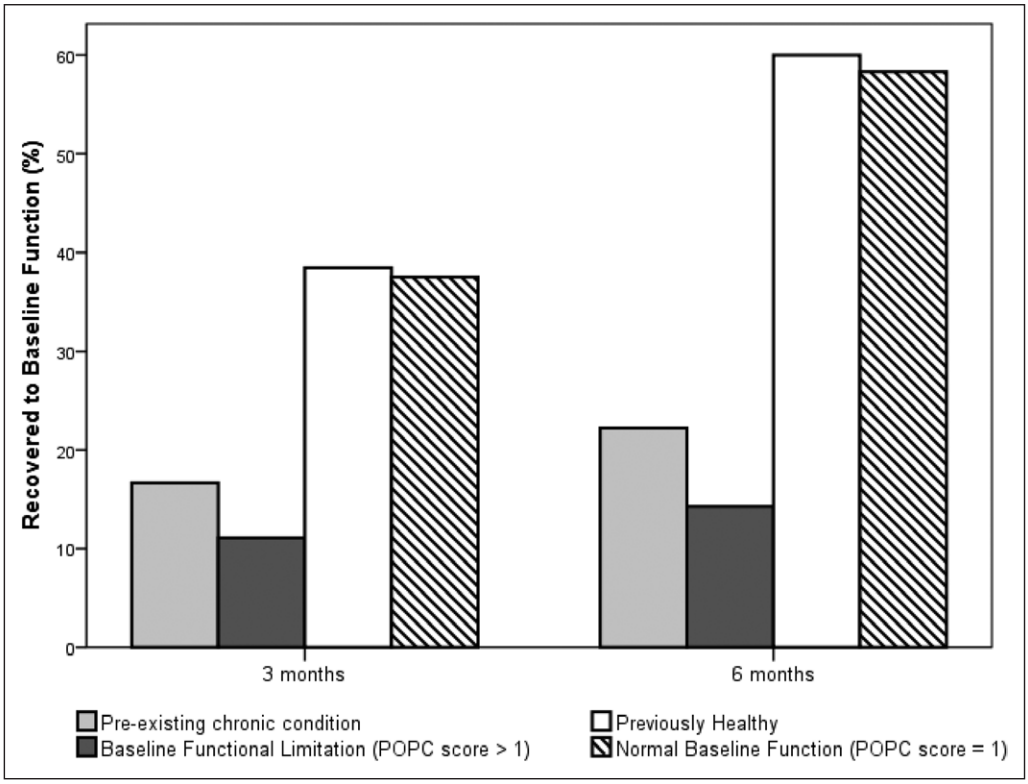

Figure 3. Proportion of patients recovering to baseline functional status at 3 and 6 mo post PICU discharge. Baseline functional limitation was defined as patients with a Pediatric Overall Performance Category (POPC) score more than 1.

Although this pilot study was underpowered to detect significant differences in the functional outcome measures, we made several important observations. Children who survive a critical illness experience a deterioration in function. This has been previously demonstrated (18); however, this study enabled us to explain functional decline at multiple levels of assessment (capabilities, performance, and home participation) and rates of recovery. This preliminary study is the first to our knowledge to apply the ICF-CY framework in the evaluation of functional recovery prospectively and explore potential predictors of recovery in critically ill children. Our exploratory analyses have generated the following hypotheses: 1) the severity of critical illness

TABLE 3. Univariate Regression Analyses Exploring Predictors of Change in Function[a]

Factors	FSS Self-Care	FSS Mobility	CAS Self-Care	CAS Mobility
Change in PEDI scores (95% CI) from baseline to 3 mo[b]				
Chronic health condition	11.7 (−3.4, 26.7)	6.0 (−11.7, 23.7)	5.0 (−12.8, 22.9)	−0.7 (−20.0, 18.6)
Baseline functional limitation[c]	10.0 (−6.0, 27.0)	10.1 (−8.1, 28.2)	2.1 (−16.2, 20.4)	−0.9 (−20.6, 18.7)
Baseline PELOD	−0.9 (−1.6, −0.2)	−0.6 (−1.6, 0.1)	−0.7 (−1.6, 0.1)	−0.4 (−1.3, 0.6)
Baseline POPC	2.6 (−3.5, 8.8)	4.7 (−2.1, 11.4)	2.0 (−5.0, 8.9)	3.1 (−4.2, 10.5)
Baseline PCPC	1.9 (−4.2, 7.9)	4.7 (−2.0, 11.3)	2.3 (−4.4, 9.1)	4.1 (−3.01, 11.3)
Change in PEDI scores (95% CI) from baseline to 6 mo[b]				
Chronic health condition	5.4 (−0.9, 11.7)	−0.01 (−11.3, 11.3)	5.9 (−3.5, 15.2)	4.7 (−2.6, 11.9)
Baseline functional limitation[c]	4.0 (−2.7, 10.7)	2.2 (−9.3, 13.7)	2.8 (−7.3, 12.9)	1.5 (−6.2, 9.2)
Increasing PELOD	−0.5 (−0.7, −0.2)	−0.6 (−1.0, −0.1)	−0.4 (−0.8, 0.1)	−0.2 (−0.6, 0.1)
Increasing POPC	1.0 (−1.5, 3.5)	1.2 (−2.9, 5.3)	−0.3 (−9.0, 8.4)	0.7 (−2.0, 3.5)
Increasing PCPC	0.7 (−1.7, 3.2)	1.3 (−2.8, 5.3)	0.7 (−3.0, 4.3)	0.9 (−1.9, 3.6)

FSS = Functional Skills Score, CAS = Caregiver Assistance Scales, PEDI = Pediatric Evaluation of Disability Inventory, PELOD = Pediatric Logistic Organ Dysfunction score, POPC = Pediatric Overall Performance Category score, PCPC = Pediatric Cerebral Performance Category score.

[a]Function is measured by the PEDI score.

[b]For each patient, the change in function was calculated by the mean difference (95% CI) in PEDI score from baseline to follow-up. Change at 3 mo ($n = 27$) = 3 mo score − baseline score; change at 6 mo ($n = 19$) = 6 mo score − baseline score. As these data are hypotheses generating, no p values are presented.

[c]Functional limitation is defined as a baseline POPC score of > 1.

Range for POPC and PCPC scores is 1–7 from 1 = normal, increasing scores indicating increasing disability, 6 = brain death, or 7 = cardiorespiratory death.

TABLE 4. Participant Clinical Outcomes and PICU-Acquired Morbidities

Variable	Total No. of Patients (*n* = 30)
Ventilator-free days (out of 28 d)	22.5 (15, 26)
Mortality, *n* (% of 33)	3 (9)
Length of PICU stay (minimum, maximum); (Q1, Q3)	10 (4, 128); (7, 16)
Length of hospital stay (minimum, maximum); (Q1, Q3)	19 (6, 170); (10, 47)
Readmission within 6 mo, *n* (%)	
Hospital ward	11 (37)
PICU	8 (27)
PICU-acquired weakness	
Suspected, *n* (%)	9 (30)
Confirmed, *n* (%)	2 (6.7)
Pressure ulcers, *n* (%)	0 (0)
PICU delirium, *n*	1
New-onset joint contractures, *n*	1
New-onset deep venous thrombosis, *n*	1

Q1 = the first quartile, Q3 = the third quartile.
Data are presented as median (Q1, Q3) unless otherwise stated.

may influence the degree of functional decline and the rate of functional recovery; 2) previously healthy children and those with normal function may experience a greater degree of functional decline than those with comorbid health conditions and baseline functional impairments; however, their capacity for functional recovery may be greater than the latter; and 3) there are aspects of "function" that may be more or less affected by critical illness, which in turn influences one's overall recovery over time. As these are pilot data, we caution against over its interpretation.

Despite the small sample size, there is a suggestion that children who survive a critical illness and their families in this study have significant ongoing needs from the healthcare system and in their natural environment. Two thirds of survivors required rehospitalization within 6 months, almost half of whom were critically ill. More children died in the 6 months post discharge than while in PICU. It is important to recognize that a significant proportion of PICU patients in this study had an underlying comorbid condition. This is consistent with previous literature (1, 3). Although preexisting chronic conditions may not be modifiable, understanding aspects of a child's functioning, such as task capability, performance, and how they reintegrate back into their home and community, identifies potential areas to support, optimize, and maintain the health, function, and recovery of critically ill children. The results of this pilot provide strong justification to evaluate these outcomes in a larger, multicenter, longitudinal study, adequately powered to evaluate predictors of functional deterioration and recovery. They also support the importance of a comprehensive framework for measuring function in this population, rather than isolated measures of physical capacity that have been previously used.

We consciously designed eligibility criteria in this study to select patients at risk of morbidity. Consequently, the clinical outcomes observed in this study cohort appear more significant than an overall PICU population (34). Interestingly, the prevalence of suspected and confirmed PICU-acquired weakness in this study is much higher than previously reported (35). We provided suggested guidelines for diagnosis of PICU-acquired weakness, which allowed for the inclusion of "suspected" diagnosis, given the challenges of confirmatory diagnosis by electrophysiologic testing and muscle biopsy in children. These results may indicate that these and the other PICU-acquired morbidities have to date been underrecognized in PICU, due to similar challenges in awareness and ascertainment. This single-center pilot sample size was too small to make any conclusions about these clinical outcomes. However, they do provide ample rationale prospectively to evaluate PICU-acquired morbidities in a larger multicenter study.

CONCLUSION

Outcomes research in pediatric critical care is evolving and most of our children survive their critical illness. The goals of care should therefore shift from only saving lives to ensuring recovery of functional health status and an optimized quality-of-life among survivors of critical illness. As the life expectancy of children is longer than adults, the value of PICU care should extend beyond survival status to understanding life after PICU. This pilot study provides evidence that applying the ICF-CY framework to measure function is feasible and relevant to critically ill children. We used the results and lessons learned from this pilot study to inform the methodology, outcomes of interest, and sample size of a larger multicenter study, which will include additional qualitative and caregiver perspectives, and health-related quality-of-life measurements, to functional recovery (ClinicalTrials.gov Identifier: NCT02148081). Only after we understand how to measure and quantify functional outcomes, can we determine the impact of PICU interventions and early rehabilitation, on functional recovery in children who survive a critical illness.

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