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Functional Recovery following Critical Illness in Children: the “Wee-cover” Pilot Study

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Abstract

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 Pediatric Intensive Care Unit (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 intensive care unit 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.

Measurements—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 (PEDI), and the Participation and Environment Measure for Children and Youth (PEM-CY).

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Author contributions

Karen Choong was responsible for the study conception and design.

Samah Al-Harbi, Katie Siu, Jan Willem Gorter, Mary Khetani, and Brian Timmons, and Lehana Thabane contributed to the study methodology and interpretation of the data.

Karen Choong, Samah Al-Harbi and Katie Siu were responsible for executing and coordinating the study, and collecting study data

Katie Wong was responsible for developing and managing the study database, and data entry

David Pogorzelski was responsible for managing the PEM data collection and entry, and interpretation of results.

Karen Choong, Ji-Cheng, Lehana Thabane were responsible for statistical analyses.

Karen Choong drafted the manuscript 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, review of the final manuscript.

The remaining authors have disclosed that they do not have any potential conflicts of interest.

Institution where the work was performed: McMaster Children’s Hospital, Hamilton, Ontario

Main results—Thirty-three patients were enrolled between October 2012 and April 2013. Consent rate was 85%, follow-up rates 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 multi-center study evaluating functional recovery in this population.

Keywords

pediatrics; critical illness; function; recovery

Introduction

Increasing numbers of children require critical care annually because of a changing spectrum of pediatric disease, technological advancements, and improved survival amongst extremely premature neonates and children with complex health conditions (1, 2). The overwhelming majority of children admitted to a Pediatric Intensive Care Unit (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 amongst 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, while 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 pre-existing 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 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 in order to assess the feasibility of our methods, and to inform the methodology of a future planned multi-centre 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 a) a minimum age (when one is expected to be gaining functional skills), and b) 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 on admission (as measured by the Pediatric Logistic Organ Dysfunction score; PELOD (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 intensive care unit 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), 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 their 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, 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 aged 6 months to 7.5 years (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 Children and Youth (PEM-CY) was used for children aged 5 to 17 years, and Young Children's version (YC-PEM) was used for children aged under 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 (see Supplemental Appendix for definitions and diagnostic criteria). Exercise tolerance was evaluated in an age-appropriate subgroup (> 4 years) prior to hospital discharge, 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 5 potential predictors of functional recovery (our planned primary outcome for the definitive study), given a minimum of 6 patients per predictor variable. We planned to use these data to inform the sample size and methods of the larger multi-center study. Baseline participant characteristics were summarized using mean (standard deviation [SD] or median (Q1, Q3) depending on the distribution. The analysis of feasibility outcomes is descriptive and reported as estimates (95% confidence intervals). 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 multi-center 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 (College Station, TX: StataCorp LP).

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) (Figure 1). There were 2 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 (5.0) years, and 16 (48%) were male. The most frequent reason for PICU admission was respiratory failure (8/33; 24%). Sixteen (48%) of these patients had a pre-existing co-morbid chronic condition (defined as the presence a medical diagnosis for at least 6 months). 15/33 (45%) and 13/33 (39%) of children had functional and cognitive limitations at baseline as determined by POPC and PCPC scores respectively.

The follow-up rate of survivors was 27/29 (93%) at 3 months and (20/28) 71% at 6 months (Figure 1). Reported reasons for loss to follow-up from the total of 8 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). Parental stress index at 3 months was a median percentile of 54 (range 1, 99) (normal range 16-80, borderline 81-84, clinically significant level of stress 85-99+ percentile)(20). Exercise testing was feasible in only 2/30 (6.7%) participants. 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, that appeared to improve over time, as measured by PEDI and POPC scores (Table 2). PEDI was able to further discriminate function according to pre-morbid condition in this population – PEDI scores in each domain were higher amongst previously healthy children than those with pre-existing chronic conditions and baseline functional limitation (Figure 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 pre-existing chronic condition and 14.3% with functional limitations prior to their critical illness recovered to baseline by 6 months, compared to 60.0% in previously healthy children and 58.3% of children with normal baseline function (Figure 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 months 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 non-discretionary activities such as school preparation, personal care, and household chores (Supplemental Digital Content - Figure 4). At 6 months, 33% of parents of children with underlying functional limitation report environmental barriers to their child’s participation at home, compared to 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 amongst the entire cohort who consented to participate was 3/33 (9%). Two of the 3 patient deaths occurred after PICU discharge at 37 and 191 days respectively. Nineteen patients (63%) required hospital readmission within 6 months of PICU discharge, 8 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 as well as 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). While 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 re-integration post-hospital 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 demonstrates that executing such a study design and outcome measurements are feasible in a single centre. The consent rate was excellent, and patient recruitment was completed one month ahead of anticipated. The eligibility criteria were appropriate in selecting a cohort of patients who may be at risk of impaired functional recovery. While 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 is 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 the need to optimize a follow-up plan to capture such patients in future studies. Lessons learned from this pilot supports 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, cognitive and functional limitations, thus questioning the utility of this test as a predictor of functional recovery in this population.

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 has generated the following hypotheses: 1) the severity of critical illness 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 co-morbid health conditions and baseline functional impairments, however their capacity for functional recovery may be greater than the latter; 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 health care system, and in their natural environment. Two-thirds of survivors required re-hospitalization 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 co-morbid condition. This is consistent with previous literature (1, 3). While pre-existing chronic conditions may not be modifiable, understanding aspects of a child’s functioning such as task capability, performance, and how they re-integrate 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, multi-center, 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 incidence 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 under-recognized 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 evaluate PICU-acquired morbidities in a larger multi-center 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 amongst 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 multi-center 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.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Figure 1. Patient Flow
PICU Pediatric Intensive Care Unit

Figure 2. Functional Status (PEDI*) over time

The boxplots represent the median and IQR while the tails indicate the minimum and maximum.

PEDI, Pediatric Evaluation of Disability Inventory (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 > 1.

Figure 3. Proportion of patients recovering to baseline functional status at 3 and 6 months post PICU discharge

Baseline functional limitation was defined as patients with a Pediatric Overall Performance Category (POPC) score > 1.

Table 1

Baseline Characteristics

Demographic Variables	Number of patients (n = 33)
Age, years; median (min, max); (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 RTI)	12 (36)
Sepsis	2 (6)
Shock	3 (9)
Trauma	4 (12)
Neurologic disorder	5 (15)
Elective post-procedure	3 (9)
Emergency Surgery	3 (9)
Other	1 (3)
Pre-existing co-morbid chronic medical diagnosis: n (%)	16 (48)
PRISM III ^a on admission; median (min, max); (Q1, Q3)	5 (0, 22); (2, 9)
PELOD ^b on admission; median (min, max); (Q1, Q3)	2 (0, 41); (1, 12)
Baseline PCPC ^d score, median (Q1, Q3)	1 (1, 4)
Distribution of Baseline PCPC scores: n (%)	
Normal (Score of 1)	20 (61)
Mild disability (Score of 2)	2 (6)
Moderate disability (3)	2 (6)
Severe disability (4)	9 (27)
Coma or vegetative state (5)	0
POPC ^c score, median (Q1, Q3)	1 (1, 4)
Distribution of Baseline POPC scores: n (%)	
Good overall performance (1)	18 (55)
Mild disability (Score of 2)	3 (9)
Moderate disability (3)	1 (3)
Severe disability (4)	11 (33)
Coma or vegetative state (5)	0

^aPRISM III: Pediatric risk of mortality III score;

^bPELOD: Pediatric logistic organ dysfunction score;

^cPCPC: Pediatric Cerebral Performance Category;

^dPOPC: Pediatric Overall Performance Category; (range for POPC and PCPC scores are 1-7 from 1=normal, increasing scores indicating increasing disability, 6 = brain death or 7 = cardiorespiratory death).

Table 2**Functional Outcomes**

	Baseline (pre-morbid)	3 months	6 months
PEDI SCORE (Scaled)^a			
FSS Self Care ^b	n = 28	n = 26	n = 20
Median (Min, Max); (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 (Min, Max); (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 (Min, Max); (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 (Min, Max); (Q1, Q3)	76.75 (0, 100); (40.9, 100)	58.8 (0, 100); (39, 100)	72.85 (0, 100); (51.05, 100)
POPC score ^d	n = 30	n = 29	n = 28
Median (Min, Max); (Q1, Q3)	1 (1, 4); (1, 4)	2 (1, 4); (1, 4)	1 (1, 4); (1, 4)
PCPC score ^e	n = 30	n = 29	n = 28
Median (Min, Max); (Q1, Q3)	1 (1, 4); (1, 4)	3 (1, 4); (1, 4)	2 (1, 7); (1, 4)

Min: minimum; Max: maximum; Q1: the 1st quartile; Q3: the 3rd quartile

^aPEDI: Pediatric evaluation of disability inventory. Scaled scores are distributed along a continuum from 0 to 100, which represent relatively easy to relatively difficult items in a domain on the 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

^bFSS: Functional skills score, self-administered. 2 patients at baseline and 1 at 3 months respectively, did not complete this portion of the PEDI

^cCAS: Caregiver assistance scales, administered by interview

^dPOPC: Pediatric Overall Performance Category Score;

^ePCPC: Pediatric Cerebral Performance Category Score. Range for POPC and PCPC scores are 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.

Table 3Univariate Regression Analyses exploring predictors of change in Function^a

^b Change in PEDI scores (95% CI) from Baseline to 3 months					
Factors	FSS selfcare	FSS mobility	CAS selfcare	CAS mobility	
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 ^d	-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 ^e	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 ^f	1.9 (-4.2, 7.9)	4.7 (-2.0, 11.3)	2.3 (-4.4, 9.1)	4.1 (-3.0, 11.3)	
^b Change in PEDI scores (95% CI) from Baseline to 6 months					
	FSS selfcare	FSS mobility	CAS selfcare	CAS mobility	
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 ^d	-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 ^e	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 ^f	0.7 (-1.7, 3.2)	1.3 (-2.8, 5.3)	0.7 (-3.0, 4.3)	0.9 (-1.9, 3.6)	

^aFunction is measured by the Pediatric Disability Index (PEDI) score; FSS: functional skills score, CAS: caregiver assistance scales.^bFor each patient, the change in function was calculated by the mean difference (95% Confidence Interval) in PEDI score from baseline to follow-up. Change at 3 months (n=27) = 3 months score – baseline score; change at 6 months (n=19) = 6 months score – baseline score. As these data are hypotheses generating, no p-values are presented^cFunctional limitation is defined as a baseline Pediatric Overall Performance Category score of > 1^dPELOD: Pediatric logistic organ dysfunction score;^ePOPC: Pediatric Overall Performance Category Score;^fPCPC: Pediatric Cerebral Performance Category Score. Range for POPC and PCPC scores are 1-7 from 1=normal, increasing scores indicating increasing disability, 6 = brain death or 7 = cardiorespiratory death

Table 4

Clinical Outcomes

	Total number of patients n=30
Ventilator-free days (out of 28 days)	22.5 (15, 26)
Mortality, n (% of 33)	3 (9%)
Length of PICU stay (min, max); (Q1, Q3)	10 (4, 128); (7, 16);
Length of hospital stay (min, max); (Q1, Q3)	19 (6, 170); (10, 47);
Readmission within 6 months; 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

Data is presented as median (Q1, Q3) unless otherwise stated.

PICU, pediatric intensive care unit