9-1-2020

Priority Outcomes in Critically Ill Children: A Patient and Parent Perspective

Nora Fayed

Saoirse Cameron

Douglas Fraser MD, PhD, FRCPC

Jill I Cameron

Samah Al-Harbi

See next page for additional authors

Authors

Nora Fayed; Saoirse Cameron; Douglas Fraser MD, PhD, FRCPC; Jill I Cameron; Samah Al-Harbi; Racquel Simpson; Maha Wakim; Lily Chiu; and Karen Choong

Priority Outcomes in Critically Ill Children: A Patient and Parent Perspective

By Nora Fayed, PhD, Saoirse Cameron, MA, Douglas Fraser, MD, PhD, Jill I. Cameron, PhD, Samah Al-Harbi, MD, Racquel Simpson, MA, Maha Wakim, MSc OT, Lily Chiu, MSc OT, and Karen Choong, MB, BCh

Background Outcomes in pediatric critical care research are typically selected by the researcher.
Objectives (1) To identify outcomes prioritized by patients and their families following a critical illness and (2) to determine the overlap between patient-centered and researcher-selected study outcomes.
Methods An exploratory descriptive qualitative study nested within a longitudinal cohort study conducted in 2 pediatric intensive care units (PICUs). Participants were purposively sampled from the primary cohort to ensure adequate demographic representation. Qualitative descriptive approaches based on naturalistic observation were used to collect data and analyze results. Data were coded by using the International Classification of Functioning, Disability, and Health Children and Youth (ICF-CY) framework.
Results Twenty-one participants were interviewed a mean of 5.1 months after PICU discharge. Outcomes fell into 2 categories: patient-centered and family-centered. In the former, diagnosis, survival, and prognosis were key priorities during the acute critical illness. Once survival appears possible, functioning (physical, cognitive, and emotional), and factors that influence recovery (ie, rehabilitation, environment, and quality of life) are prioritized. Family-centered outcomes consisted of parents' psychosocial functioning and experience of care. Patient-centered outcomes were covered well by the selected study measures of functioning, but not by the clinical outcome measures.
Conclusion Functioning and quality of life are key patient-centered outcomes during recovery from critical illness. These are not well captured by end points typically used in PICU studies. These results justify the importance of patient- and family-centered outcomes in PICU research and a need to determine how these outcomes can be comprehensively measured. (*American Journal of Critical Care.* 2020;29:e94-e103)

doi:https://doi.org/10.4037/ajcc2020188

Patient-centered outcomes research is now recognized as an essential part of critical care research.[1,2] To date, most clinical trials conducted in critically ill patients have been focused on outcomes deemed important by researchers,[3,4] and patient-centered outcomes have rarely been included as end points.[4] Mortality has traditionally been considered the definitive patient outcome in critical care.[5] However, pediatric intensive care unit (PICU) mortality rates have decreased significantly with time, and thus more children are surviving with newly acquired morbidities and persistent functional and quality-of-life limitations.[6,7] Mortality is therefore no longer the stand-alone indicator of effectiveness or quality of PICU care.[8]

The emergence of PICU-acquired morbidities and the long-term impact of critical illness on children have highlighted marked knowledge gaps in our understanding of patient- and family-centered outcomes in pediatric critical care. Critical care research is therefore shifting its focus from short-term outcomes to evaluating longer-term, patient-centered outcomes and how best to measure these. However, few researchers have assessed the opinions of patients and their family members on what these outcomes should be both during the course of the critical illness and on through to recovery.

Patient-centered outcomes, which we define in this study as outcomes deemed important by pediatric patients and their family caregivers,[9] have not been adequately evaluated in the PICU population. The primary objective of this qualitative study was to identify patient-centered outcomes in children and families who survived a critical illness, from during the PICU admission to after discharge from the unit. Our secondary objective was to determine if the outcome measures selected by researchers for the primary study covered the outcomes prioritized by patients and families.

About the Authors

Nora Fayed and Karen Choong contributed equally to the execution of this study and the writing of this manuscript. **Nora Fayed** is an assistant professor, **Maha Wakim** and **Lily Chiu** are occupational therapy students, School of Rehabilitation Therapy, Queen's University, Kingston, Ontario, Canada. **Saoirse Cameron** is a research coordinator and **Douglas Fraser** is a professor, Department of Pediatrics, Western University, and Lawson Health Research Institute, London, Ontario, Canada. **Jill I. Cameron** is an associate professor, Department of Occupational Science and Occupational Therapy, Rehabilitation Sciences Institute, Rehabilitation Sciences, University of Toronto, Canada. **Samah Al-Harbi** is an assistant professor, Department of Pediatrics, King Abdulaziz University, Jeddah, Saudi Arabia. **Racquel Simpson** is a research coordinator and **Karen Choong** is a professor, Department of Pediatrics and Critical Care, Department of Health Research Methods, Evidence, and Impact, McMaster University, Hamilton, Ontario, Canada.

Corresponding author: Karen Choong, MB, BCh, MSc, McMaster Children's Hospital, 1280 Main St W, Rm 3E-20, Hamilton, Ontario, L8S4K1 (email: choongk@mcmaster.ca).

Materials and Methods

Study Design and Participants

This qualitative study was nested within a larger prospective longitudinal study evaluating functional recovery in critically ill children ("Weecover" study, ClinicalTrials.gov Identifier: NCT02148081 https://clinicaltrials.gov/ct2/show/NCT02148081).[6] The study was approved by the institutional research ethics boards and conducted at 2 participating sites: McMaster Children's Hospital and London Health Sciences Centre, Ontario, Canada. A purposive sample of participants from the Weecover study was approached for consent to participate in qualitative interviews; this method of sampling was to ensure adequate representation of a general medical-surgical PICU population demographic in terms of diversity in age, sex, diagnosis, severity of illness, and preexisting comorbidity.

> Patient-centered outcomes as prioritized by patients and their families have not been adequately evaluated in the pediatric intensive care population.

A single trained interviewer at each study site (R.S. and S.C.), not involved in the care of the patient, conducted in-depth interviews between 3 and 6 months after PICU discharge. The interview timing allowed patients and their families to reflect on their journey from critical illness to recovery. An interview guide (Table 1) was used to elicit patients' and/or their parents' priorities during their PICU admission and on through to their recovery period following hospital discharge. Interviews were conducted with additional participants until data saturation was reached. Qualitative descriptive approaches based on naturalistic observation were used to collect data

Table 1
Priority outcomes interview guide

You have volunteered to take part in this interview. We thank you so much! We really would like to understand what you have been through, and we believe that your input will not only help doctors but also other families going through a similar experience. We haven't seen you in a while, and we are really interested in how things have been since you were discharged from the pediatric intensive care unit (PICU).

Our objectives are to understand your ideas of what is important for [name's] health and well-being. So my questions will be about learning what was most important to his/her health throughout these past few months.

1. How is (name) doing now?
2. We want to give you the chance to reflect on your journey. If you can, and if you are comfortable . . .
   a. Take me back to before your child was admitted into ICU . . . what sorts of things were important to you and your family, prior to (name's) admission to PICU in (month)
   b. What sorts of things were important to you during the time you were in the PICU?
   c. What sorts of things are important to you now?
3. Have these/your priorities changed over time? What has changed since then? And what has stayed the same?
4. What does (the child) think about that? Would [child's name] see it the same way? Do you think he would agree with or disagree with what we talked about?
5. Closing questions:
   a. If you could make a recommendation to health providers to help improve how they work with families like yours, what would that be?
   b. Is there anything else you would like to tell us about your experience in the PICU?

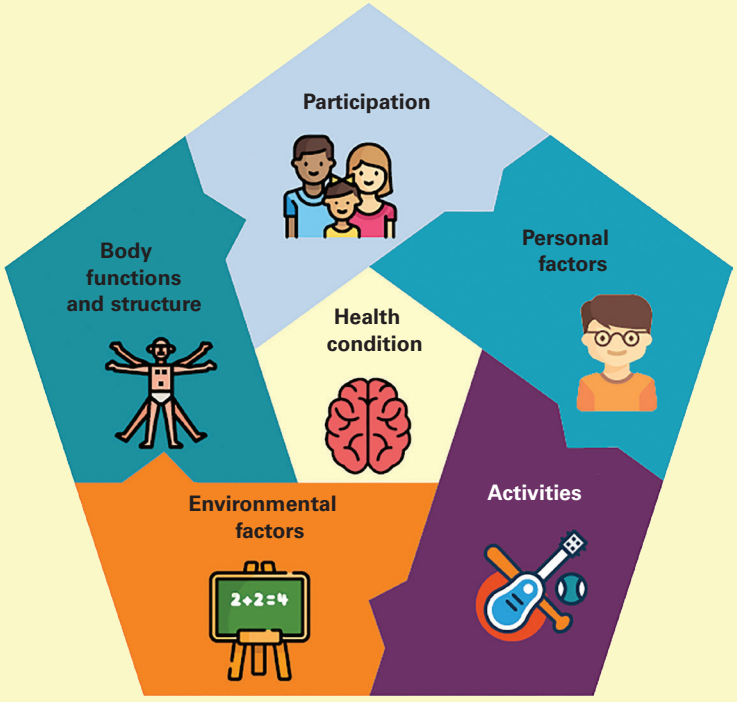

Figure International classification of functioning, disability, and health domains.

Reproduced from *ICF: A Hands-on Approach for Clinicians and Families*,[20] with permission from Dr. Olaf Kraus de Camargo and Mac Keith Press.

and analyze the results.[10,11] Audio-recorded interviews were transcribed verbatim and reviewed for accuracy, and Max QDA10 software supported data analysis.

Researcher-selected study outcomes and the respective measurement tools used in the WeeCover study were coded and thereafter mapped to the patient-centered outcomes that were determined through qualitative interviews. The study outcomes consisted of the following: clinical outcomes—that is, mortality, length of stay, and severity of illness (scores on the Pediatric Logistic Organ Dysfunction-2 and the Pediatric Risk of Mortality III)[12,13]; and functional outcomes—such as functional status (Pediatric Evaluation of Disability Inventory computer-adaptive test; PEDI-CAT),[14,15] participation (Participation and Environment Measure Child and Youth version; PEM-CY),[15] health-related quality-of-life (HRQoL; using KIDSCREEN),[16] and parental stress (Pediatric Inventory for Parents).[17] The Standards for Reporting Qualitative Research checklist was applied in the reporting of this study.

Analysis

We applied the World Health Organization International Classification of Functioning, Disability, and Health for Children and Youth (ICF-CY) framework to code both the qualitative interviews and the WeeCover study outcome measures.[18] The ICF-CY is designed to comprehensively describe and classify functioning and health; it enables the organization and reporting of outcomes according to standard definitions,[19] and it allows for mapping of content from qualitative interviews to the quantitative study outcome measures. Essential domains of the ICF-CY are as follows (see Figure)[20]: health condition, body functions and structures (includes physical, cognitive, and psychological function), activities and participation (ie, things children do in order to function in

Table 2
Characteristics of children who were patients in the study

Pseudonym	Age, y	Sex	PICU admission diagnosis	Preexisting chronic illness	PRISM-III score[a]	Days in PICU	Days in hospital	Time of interview after PICU discharge, months
Kelly	1.5	Female	Bronchiolitis	None	4	4	5	3
Gertrude	2.0	Female	Status epilepticus	None				5.5
Evan	2.1	Male	Neuroblastoma	None				3
John	2.5	Male	Septic shock	None	12	3	8	7
Harrison	2.75	Male	Hemolytic-uremic syndrome	None				3.5
Allen	12.2	Male	Pneumonia	None	2	4	6	12
Dave	12.75	Male	Trauma	None	5	6	14	6
Daniel	15.7	Male	Stroke	None	4	8	10	3.5
Chrissi	15.8	Female	Trauma	None	12	3	16	5
Adrian	17.7	Male	Myocarditis	None	3	4	4	6
Leaticia	3.2	Female	Laryngotracheal reconstruction	Developmental delay; gastroesophageal reflux	0	15	20	4.5
Joey	3.8	Male	Pleural effusion	Metastatic hepatoblastoma	0	11	19	3.5
Cate	4.75	Female	Status epilepticus	Microcephaly; spastic dystonic diplegia	5	4	19	9
Bob	7.25	Male	Pneumonia	Asthma				3
Tracey	9.6	Female	Status asthmaticus	Asthma	0	6	6	4
Gabriel	11.8	Male	Respiratory failure	Schwartz-Jampel syndrome	7	21	21	3.5
Brody	12.2	Male	Septic shock	Trisomy 21, epilepsy	7	44	81	7
Alice	14.5	Female	Pneumonia	CHARGE syndrome; long-term tracheostomy and ventilator dependence	8	3	3	6
Jake	14.5	Male	Aspiration pneumonia	Spastic cerebral palsy; neonatal kernicterus	13	14	16	3
Lenny	15.3	Male	Aspiration pneumonia	Pallister-Killian syndrome	7	24	64	3.5

Abbreviation: PICU, pediatric intensive care unit.
[a]Pediatric Risk of Mortality score third generation.[12]

their daily lives, such as mobility, self-care, and social interaction), environmental factors (physical or interpersonal facilitators and barriers to functioning), and personal factors (expectations, priorities, and quality of life).

Both the qualitative interviews and the study outcomes were coded by 2 independent coders using the ICF-CY framework and a standard method of content analysis validated for mapping qualitative information to outcomes.[21,22] Two analysts, trained in the method, coded the interviews independently and then met to resolve disagreements. Interview content requiring additional expertise was coded by a relevant member of the research team, (eg, K.C. for intensivist expertise). All codes and interview content were checked by an expert in the method (N.F.). The codes were grouped into themes and subthemes according to the ICF-CY domains. In the event that the data could not be coded by using ICF-CY, a new inductive code was generated and contrasted with the existing codes using the constant comparative method,[23] and the same inductive procedure was followed to aggregate the codes into themes. Following coding of the study outcome measures and themes derived from the qualitative data, we assessed the degree of overlap between the study outcomes and the patient-centered outcomes.

Results

Of 178 patients and families approached from the Weecover study, 160 (89.9%) consented to be contacted in the future for an interview. From these, we interviewed a total of 21 participants: 20 parents (19 mothers; 1 father), and 1 patient (Adrian), representing a total of 20 critically ill children, 10 (50%) of whom had a preexisting chronic medical condition (Table 2). The majority of patient participants either deferred to their parents during the interviews or were not physically or cognitively able to participate in the interviews. Interviews were conducted 3.5 to 12 months (mean [SD], 5.08 [2.29] months) after discharge.

The outcomes that were considered priorities for patients, as expressed by the patient or by his/her parent (patient-centered outcomes), are presented according to their themes and categorized according to ICF-CY domains, along with exemplar quotations where appropriate. As the overwhelming majority of interviewees were parents, we uncovered additional important outcomes that referred more specifically to the family as a unit. These are categorized as family-centered outcomes.

Patient-Centered Outcomes

Early in the PICU admission, survival is a top priority. Parents expressed the need to understand their child's diagnosis, the therapeutic options, and ultimately if their child will survive. Priorities appear to evolve during the course of critical illness from survival to other important themes.

Theme 1: Survival (ICF-CY Domain: Health Condition). The fear of death is paramount early in the acute period of critical illness.

> I don't know if she's gonna live. I don't know if she's gonna die. I hear beep beep beep, I see all these needles, everything. But when you walk into your child's room day after day, hour after hour, and these same 4 walls with no windows, it's dark and you're scared.
> –Cate's mother

> Making sure my kid stayed alive. 'Cause it was really touch and go there for a while, right?
> –Dave's mother

Although arriving at a diagnosis was a priority, parents sometimes feared the prognosis, especially if it was not compatible with survival:

> I see that maybe we won't get a diagnosis. I'm kind of prepared for that. It's like you get your hopes up so many times and you don't get that answer. I've been sad about it a few times, but let's say we get a diagnosis and it's something really rare and it's not treatable. What good is it to me anyways, right?
> –Cate's mother

Theme 2: Functional Recovery. When survival becomes apparent, families turn their priorities to functional recovery. The domains of functioning that parents considered most important in their child's recovery are multidimensional and are presented here according to the ICF-CY domains.

Domain: Body Functions. Parents prioritized physical and mobility function and the need for rehabilitation strategies to help their child recover both within and beyond the PICU. This prioritization was done for both previously healthy children and for children with underlying functional disabilities.

> I just want her to get up, I don't want her to have a hip replacement, I don't want her to have rods in her arm for the rest of her life and she can only lift it so far. I want her to be able to function normally again.
> –Chrissi's mother

> I guess it's hard to continue a physical regime but maybe the physiotherapist should, for long-term patients check, so that everything doesn't get stuck, arms and hands in a curled-up position because the kids aren't moving.
> –Lenny's mother

The ability for their children to regain not just their physical, but cognitive and emotional functioning was repeatedly expressed as important. These symptoms and the support needed became more apparent in the post-PICU period:

> A couple times just after we got home he woke up with dreams, and he's like that he was having nightmares that they were putting the tube in again and stuff right? . . . he just remembers bits and pieces of it, but he'll tell you he doesn't want to come back to the hospital.
> –Gabriel's mother

Domain: Activities and Participation. The ability for their children to return to their daily life routines and participate in their home, social, and school activities were priority outcomes. Activities of daily living were often presented according to the functional capacity and needs of the individual child, such as mobility (eg, transfers, walking), communication, and self-care.

> Getting back into his world . . . and day to day routine. . . . He's come a long, long way, but it's hard.
> –Daniel's mother

> I want him to be healthy and I want him to eventually get back into the school setting so he has that social aspect. He gets to see his friends, he gets his education.
> –Gabriel's mother

Participation in social activities was important and meaningful, even if their child's health condition could not be cured:

> What can we do to, you know, get him a more normal life so he's not always sick and in here? 'Cause you know, his life is going by and you know, he misses out on stuff.
> –Brody's mother

Domain: Environmental Factors. Parents reported that the PICU environment affected their child's sleep and psychological and emotional functions. Hence, an environment that facilitates recovery is crucial:

> Her trying to sleep in a hospital with lights and sounds and movements—she was not having it. It was also a little tough because when she was better, she was very restless; she doesn't sit calmly and do anything.
> –Kelly's mother

> I found that he was happier if I was making sure that . . . like changing different sceneries and stuff like that. Not looking at the same 4 walls you know?
> –Gabriel's mother

Domain: Health Condition. Optimizing and maintaining their child's health condition following recovery from critical illness was extremely important to parents. There was perpetual fear that new symptoms may signal a recurrence of critical illness.

> Keeping him healthy is important now, because I don't want to have to do this again and I've already been warned once you're in the PICU the chances of returning increase every time you're in. Well we've been in twice now.
> –Bob's mother

> When she coughs now, I'm like oh my gosh why are you coughing? Why are you sick? You think, . . . oh my God, is this going to be the one that sends her in again?
> –Tracey's mother

Theme 3: Quality of Life. Quality of life and emotional well-being were key outcomes that patients and families prioritized both during critical illness and in the post-PICU period. Parents often expressed the need to ensure their child's comfort and minimize suffering. The impact of the illness on the child's quality of life was influenced by life expectations and their baseline health condition and level of functioning.

> As soon as I was told no activity, then I was like just what am I going to do with myself? What am I going to do with my life? Oh my god, all dreams crushed and gone . . .
> –Adrian

> My main goal is always that she's happy. Alice's got a life history of having to deal with major challenges. . . . I've always tried to give her an environment, no matter where it is, even in hospital.
> –Alice's mother

Family-Centered Outcomes

Some of the priorities raised by parents were based on the experience of their child's critical illness and recovery, and those priorities pertain to the family as a unit and cannot be clearly separated from the child. These fell into 2 themes: family psychosocial outcomes and family experience of care.

Theme 4: Family Psychosocial Outcomes. Parents often struggled to cope with their child's critical illness and reported their own physical and emotionally distressing symptoms:

> I really was so anxious. I was getting nightmares and I'd wake up in a, a sweat and couldn't sleep. . . . and it's funny, because I said to my husband, I think I'm really having side effects from what happened.
> –Harrison's mother

A source of distress was the uncertainty of their role while their child was being cared for by others in the PICU, and what they should or could do to help their child:

> I think the hardest thing to do was to kind of figure out my place and what I could do because she was so not there. I couldn't really do much and I didn't know if I should stay or go home, what I should feel comfortable doing or bringing or communicating.
> –Kelly's mother

The impact of the child's critical illness on siblings was also of key importance and was repeatedly expressed by every affected family. Parents identified their difficulties with focusing on their critically ill child while balancing the demands and responsibilities to the rest of their family, their work, and their home. Hence length of stay was important to them

as it related not only to their child's outcome, but to their finances and work commitments.

> You know the truth is, I was actually really torn about making sure that she was getting the right care and what was going on at the house without me just because I have such a little one and he was 2 and you know that was the first time I had ever been away from him. So I had to give one up and really it was a struggle, it was really hard.
> –Tracey's mother

> This takes a toll on your finances because you have both parents working, one has to stop working, I mean there's no other way. So you lose one income, you lose a lot—and if you need 2 parents who need to work . . . I mean you're talking about really struggling financially.
> –Joey's mother

Theme 5: Family Experience and Supports. Families expressed the need for specific supports both during their hospitalization and during recovery following hospital discharge. While in the hospital, they valued basic necessities such as parking, sleeping accommodations, transportation, internet, and social support services. Following discharge, they needed social services, educational support, and legal services. Parents also desired and valued a supportive attitude from the health care team, such as regular, clearly communicated updates,continuity of care, and accurate transfer of information among the members of the health care team. Some parents expressed that their expertise should be acknowledged and that they should be engaged in shared decision-making for their child:

In addition to the needs of their child, parents prioritize communication, social and financial support, and family well-being.

> You know how many hours of research went into me being ballsy enough to ask you to do that, and you said no . . . Why, why did you choose that? . . . Because maybe you're seeing something in my child that I didn't see? . . . You're, they're getting a glimpse of Cate for (pause) a few days in here. I've had a glimpse of her every morning, 24 hours a day, 7 days a week for 5 years.
> –Cate's mother

Mapping of Patient- and Family-Centered Outcomes to Study Outcome Measures

The outcome measures selected in the primary study were of 2 categories—clinical outcomes and functional outcomes—whereas the patient- and family-centered priority outcomes are summarized as they pertain to the child and the family, respectively (Table 3). Patient-centered priorities that pertained to survival (ICF-CY domain: health condition) had 66% coverage by the primary study's clinical outcome measures. Patient-centered priorities related to functioning had 80.4% coverage (as measured by PEDI-CAT), and those related to participation and quality of life had 95% coverage (measured by PEM-CY and KIDSCREEN). As for the family-centered priority outcomes, family needs had only 45.5% coverage and family experience had only 42.9% coverage (measured with the Pediatric Inventory for Parents). Two patient-centered outcomes were not covered by any of the study outcome measures: "pain" and "strategies for rehabilitation."

Discussion

Patients and families have unique perspectives that should be considered and integrated in order to make research and health decisions relevant.[24] This qualitative study is the first we know of to qualitatively identify the outcomes deemed most important during and following critical illness in children, as expressed primarily by their parents. The results reveal the following key findings: (1) Patient-centered outcomes are multidimensional and evolve from the acute period in the PICU to the post-PICU period. Diagnosis, survival, and prognosis are key priorities early in the acute presentation of critical illness, whereas functioning (physical, emotional, and psychosocial), quality of life, and rehabilitation needs are the focus once survival is clear and during longer-term recovery; (2) There are numerous family-centered outcomes in addition to the child's that affect a family's coping, well-being, and functioning and may influence the family's ability to support the child's journey from critical illness to recovery; (3) The clinical outcomes traditionally used in PICU research do not adequately cover the outcomes that patients and their families prioritize; functional outcome measures more comprehensively capture patient and family priorities both before and after PICU discharge. A significant limitation of this study is that the majority of perspectives are from parents, reflective of the minority of children who were able or willing to participate in the interviews. We found that although patients may assent, they preferred to defer to their

Table 3
Mapping of patient- and family-centered outcomes to the study's outcome measures

Patient- and family-centered priorities	While in PICU	After PICU discharge	Study outcome measures: Functional	Study outcome measures: Clinical
Child Health condition; organ function; survival	√	√	PEDI-CAT	Mortality, PELOD-2; PRISM III
Physical function	√	√	PEDI-CAT	Not covered
Cognitive and emotional function	√	√	PEDI-CAT; KIDSCREEN	
Mobility	√	√	PEDI-CAT	
Self-care, activities of daily living		√		
Quality of life	√	√	KIDSCREEN	
Communication, behavior, stress management	√	√	PEM-CY	
Social supports and relationships	√	√		
Participation at home, social, school, and community		√		
Length of hospital stay (time away from home, work, family)	√	NA	Not covered	Length of stay
Strategies for the child's rehabilitation	√	√		Not covered
Physical pain	√	√		
Family Parenting role	√	√	PIP	
Parental physical and emotional health	√	√		
Concerns about family and their needs	√	√		
Finances, employment	√	√		
Family experience	√	√		

Abbreviations: KIDSCREEN, a generic pediatric health-related quality of life measure; NA, not applicable; PEDI-CAT, Pediatric Evaluation of Disability Inventory, Computer Adaptive Test; PELOD-2, Pediatric Logistic Organ Dysfunction-2; PEM-CY, Participation and Environment Measure, Child and Youth version; PICU, pediatric intensive care unit; PIP, Pediatric Inventory for Parents; PRISM III, Pediatric Risk of Mortality III score.

parents at the time of the interview. The results should therefore be interpreted in this context.

The majority of adult and pediatric critical care studies to date measure only short-term, clinical outcomes such as organ dysfunction and severity of illness.[3,4] Although those outcomes are important, this study demonstrates that these physiologically based outcomes cover only a portion of what children and families prioritize and omit the majority of patient-centered outcomes that extend beyond survival to the post-PICU period. Survival and recovery from critical illness are complex, involving biological, psychological, and social elements, all of which require different levels of attention at different times in the recovery process.[5,25,26] Although biological, clinical outcomes are important in the resuscitation and stabilization phases of critical illness, they do not cover much of what is important to patients during recovery, such as functioning, participation, and quality of life. Recent survey data suggest that clinicians agree with family members that quality of life and functional outcomes should be prioritized in PICU research,[27] a concept that is increasingly acknowledged in publications about the adult ICU.[28] The results of this study are therefore important; they justify the need to measure outcomes that are important to patients and illustrate how these outcomes can be measured in a longitudinal pediatric critical care study.[6] This study emphasizes the importance of redefining "definitive" outcomes for PICU research.

Although the study outcomes did cover much of the patient priorities, 2 outcomes of note were not covered at all: pain and rehabilitation strategies in the post-PICU period. The selection of outcomes when evaluating the effectiveness, impact, and quality of critical care interventions should ideally be tailored to the specific research question, be responsive to the intervention under evaluation,[29] and be reflective of outcomes prioritized by patients and families, rather than restricted to those outcomes prioritized only by clinicians and researchers. Emerging PICU trials

> Family-centered outcomes are of central importance as they affect a child's outcome and recovery.

are therefore evolving from selecting mortality or physiological primary end points to measuring functional outcomes and HRQoL.[30-32] Measuring patient-centered outcomes in critical care trials is complex; there is a tendency to oversimplify and represent a complex, multidimensional construct with a composite measure or score. Current work is underway engaging researchers as well as patient and family stakeholders to develop core outcomes sets and determine how best to measure them in PICU studies.[33]

This study also provides qualitative evidence of persistent physical, cognitive, and emotional symptoms in critically ill pediatric survivors that we now refer to collectively as the post–intensive care syndrome–pediatrics (PICS-p), and this study also shows that family members can experience significant burden and psychosocial sequelae (PICS-family).[34,35] Furthermore, the supports needed by families and their experience of care in the PICU are often overlooked, and these factors were only partially captured by a single measurement tool in the primary study (PIP). Parental stress during a child's critical illness is among the highest of all childhood illnesses, and parental stress is an independent predictor of a longer hospital stay,[6] whereas family support shortens ICU stay.[36] Family-centered outcomes are therefore of central importance as they affect a child's outcome and recovery.[6,35] Structured interventions and evidence-based guidelines have been developed to optimize family-centered care and families' experience in the critical care setting.[37] How best to screen for and manage families after discharge remains unclear; few outpatient follow-up studies have been focused on the needs of family members, and data on the uptake and effectiveness of family interventions are mixed.[38]

Researcher-selected clinical outcomes currently do not adequately cover much of what is important to patients and families following critical illness.

Although it has received much attention, little guidance is available on how to design and conduct patient-centered outcomes research in the PICU. This study provides evidence that the ICF-CY is an appropriate model for guiding measurement of patient-centered outcomes in critical care, as it is in multiple other settings.[39,40] The ICF-CY does not, however, cover the experience of care, which as we have described, is crucial to outcomes for both patients and families.[41] Although the ICF-CY does feature the family in the child's environment, we chose to present family outcomes as a separate theme given the wealth of this data. It was at times impossible to distinguish the impact on the patient from the impact on the family, as the patient-family dyad is often inseparable.

Conclusions

Improving survivorship starts with understanding what outcomes are important to survivors. This study reveals novel, important findings that patient- and family-centered outcomes following critical illness in children extend far beyond survival, and are focused on functioning, HRQoL, a healing environment, and rehabilitation. The study also illustrates the persistent and distressing psychological and emotional impact that critical illness has on families as well as pediatric patients, which is currently not being addressed within the PICU paradigm of acute care. This study justifies the need for clinicians to introduce measurement tools to more comprehensively evaluate the impact and quality of the care provided and to develop a better mechanism to screen for PICS-p during follow-up. This study also prompts researchers to include patient- and family-centered outcomes as important end points when evaluating the efficacy of PICU-based interventions.

ACKNOWLEDGMENTS

We would like to acknowledge and thank the patients and their families for sharing their experiences with us and participating in this study.

FINANCIAL DISCLOSURES

This study was funded by an Academic Health Sciences Alternate Funding Plan Innovation Grant (HAHSO Grant no. 3576.3014214; AMOSO Grant no. INN14-001).

SEE ALSO

For more about outcomes in critically ill children, visit the *Critical Care Nurse* website, **www.ccnonline.org**, and read the article by Pasek et al, "Important Outcomes for Parents of Critically Ill Children" (June 2019).

REFERENCES

1. Odetola FO. Outcomes research in the PICU. In: Wheeler DS, Wong H, Thomas P, eds. *Pediatric Critical Care Medicine.* 2nd ed. Springer-Verlag; 2014:107-116.
2. Angus DC, Mira JP, Vincent JL. Improving clinical trials in the critically ill. *Crit Care Med.* 2010;38(2):527-532.
3. Duffett M, Choong K, Hartling L, et al. Randomized controlled trials in pediatric critical care: a scoping review. *Crit Care.* 2013;17(5):R256.
4. Gaudry S, Messika J, Ricard JD, et al. Patient-important outcomes in randomized controlled trials in critically ill patients: a systematic review. *Ann Intensive Care.* 2017; 7(1):28.
5. Namachivayam P, Shann F, Shekerdemian L, et al. Three decades of pediatric intensive care: who was admitted, what happened in intensive care, and what happened afterward. *Pediatr Crit Care Med.* 2010;11(5):549-555.

6. Choong K, Fraser D, Al-Harbi S, et al. Functional recovery in critically ill children, the "WeeCover" Multicenter Study. *Pediatr Crit Care Med.* 2018;19(2):145-154.
7. Pinto NP, Rhinesmith EW, Kim TY, Ladner PH, Pollack MM. Long-term function after pediatric critical illness: results from the survivor outcomes study. *Pediatr Crit Care Med.* 2017;18(3):e122-e130.
8. Schneider E. Measuring mortality outcomes to improve health care: rationale use of ratings and rankings. *Med Care.* 2002;40(1):1-3.
9. Frank L, Basch E, Selby JV; for the Patient-Centered Outcomes Research Institute. The PCORI perspective on patient-centered outcomes research. *JAMA.* 2014;312(15):1513-1514.
10. Sandelowski M. Whatever happened to qualitative description? *Res Nurs Health.* 2000;23(4):334-340.
11. Thorne S, Kirkham SR, O'Flynn-Magee K. The analytic challenge in interpretive description. *Int J Qual Methods.* 2004; 3(1):1-11.
12. Pollack M, Patel K, Ruttimann U. PRISM III: an updated Pediatric Risk of Mortality score. *Crit Care Med.* 1996;24(5):743-752.
13. Leteurtre S, Duhamel A, Salleron J, et al. PELOD-2: An update of the PEdiatric Logistic Organ Dysfunction Score. *Crit Care Med.* 2013;41(7):1761-1773.
14. Mancini MC, Coster WJ, Amaral MF, Avelar BS, Freitas R, Sampaio RF. New version of the Pediatric Evaluation of Disability Inventory (PEDI-CAT): translation, cultural adaptation to Brazil and analyses of psychometric properties. *Braz J Phys Ther.* 2016;20(6):561-570.
15. Coster W, Law M, Bedell G, et al. School participation, supports and barriers of students with and without disabilities. *Child Care Health Dev.* 2013;39(4):535-543.
16. Michel G, Bisegger C, Fuhr DC, Abel T, KIDSCREEN Group. Age and gender differences in health-related quality of life of children and adolescents in Europe: a multilevel analysis. *Qual Life Res.* 2009;18(9):1147-1157.
17. Streisand S, Braniecki S, Tercyak K, Kazak A. Childhood illness-related parenting stress: the Pediatric Inventory for Parents. *J Pediatr Psychol.* 2001;26(3):155-162.
18. World Health Organization. *International Classification of Functioning, Disability and Health: Children & Youth Version (ICF-CY).* World Health Organization; 2007.
19. Huber EO, Tobler A, Gloor-Juzi T, Grill E, Gubler-Gut B. The ICF as a way to specify goals and to assess the outcome of physiotherapeutic interventions in the acute hospital. *J Rehabil Med.* 2011;43(2):174-177.
20. Kraus de Camargo O, Simon L, Ronen GM, Rosenbaum PL, eds. *ICF: A Hands-on Approach for Clinicians and Families.* Mac Keith Press; 2019.
21. Cieza A, Fayed N, Bickenbach J, Prodinger B. Refinements of the ICF Linking Rules to strengthen their potential for establishing comparability of health information. *Disabil Rehabil.* 2016:1-10.
22. Fayed N, Cieza A, Bickenbach J. Illustrating child-specific linking issues using the Child Health Questionnaire. *Am J Phys Med Rehabil.* 2012;91(13):S189-S198.
23. Glaser BG. The constant comparative method of qualitative analysis. *Soc Probl.* 1965;12(4):436-445.
24. Washington A, Lipstein S. The Patient-Centered Outcomes Research Institute: promoting better information, decisions and health. *N Engl J Med.* 2011;365(e31):1-3.
25. Manning JC, Pinto NP, Rennick JE, Colville G, Curley MA. Conceptualizing post intensive care syndrome in children—the PICS-p framework. *Pediatr Crit Care Med.* 2018;19(4):298-300.
26. Rennick JE, Johnston CC, Dougherty G, Platt R, Ritchie JA. Children's psychological responses after critical illness and exposure to invasive technology. *J Dev Behav Pediatr.* 2002; 23(3):133-144.
27. Merritt C, Menon K, Agus MSD, et al. Beyond Survival: Pediatric Critical Care Interventional Trial Outcome Measure Preferences of Families and Healthcare Professionals. *Pediatr Crit Care Med.* 2018;19(2):e105-e111.
28. Dinglas VD, Faraone LN, Needham DM. Understanding patient-important outcomes after critical illness: a synthesis of recent qualitative, empirical, and consensus-related studies. *Curr Opin Crit Care.* 2018;24(5):401-409.
29. Coster WJ. Making the best match: selecting outcome measures for clinical trials and outcome studies. *Am J Occup Ther.* 2013;67(2):162-170.
30. Vet NJ, de Wildt SN, Verlaat CW, et al. Short-term health-related quality of life of critically ill children following daily sedation interruption. *Pediatr Crit Care Med.* 2016;17(11): e513-e520.
31. Killien E, Reid W, Farris W, et al. Health-related quality of life among survivors of pediatric sepsis. *Pediatr Crit Care Med.* 2019;20(6):501-509.
32. Verstraete S, Verbruggen S, Hordijk J, et al. Long-term developmental effects of witholding parenteral nutrition for 1 week in the paediatric intensive care unit: a 2-year follow-up of the PEPaNIC international, randomised, controlled trial. *Lancet Respir Med.* 2018;7(2):141-153.
33. Fink EL, Jarvis JM, Maddux AB, et al. Development of a core outcome set for pediatric critical care outcomes research. *Contemp Clin Trials.* 2020 Apr;91:105968. doi: 10.1016/j.cct. 2020.105968. Epub 2020 Mar 5
34. Watson RS, Choong K, Colville G, et al. Life after critical illness in children-toward an understanding of pediatric post-intensive care syndrome. *J Pediatr.* 2018;198:16-24.
35. Manning JC, Pinto NP, Rennick JE, Colville G, Curley MAQ. Conceptualizing post-intensive care syndrome in children—the PICS-p framework. *Pediatr Crit Care Med.* 2018;19(4): 298-300.
36. Lee HW, Park Y, Jang EJ, Lee YJ. Intensive care unit length of stay is reduced by protocolized family support intervention: a systematic review and meta-analysis. *Intensive Care Med.* 2019;45(8):1072-1081.
37. Davidson JE, Aslakson RA, Long AC, et al. Guidelines for family-centered care in the neonatal, pediatric, and adult ICU. *Crit Care Med.* 2017;45(1):103-128.
38. Teixeira C, Rosa RG. Post-intensive care outpatient clinic: is it feasible and effective? A literature review. *Rev Bras Ter Intensiva.* 2018;30(1):98-111.
39. Grill E, Quittan M, Fialka-Moser V, et al. Brief ICF Core Sets for the acute hospital. *J Rehabil Med.* 2011;43(2):123-130.
40. Muller M, Grill E, Stier-Jarmer M, et al. Validation of the comprehensive ICF core sets for patients receiving rehabilitation interventions in the acute care setting. *J Rehabil Med.* 2011;43(2):92-101.
41. Banka G, Edgington S, Kyulo N, et al. Improving patient satisfaction through physician education, feedback, and incentives. *J Hosp Med.* 2015;10(8):497-502.