



# PROGNOSTIC CONVERSATIONS BETWEEN PARENTS AND PHYSICIANS IN THE PEDIATRIC INTENSIVE CARE UNIT

By Lauren Rissman, MD, Sabrina Derrington, MD, MA, and Kelly N. Michelson, MD, MPH

**Background** Up to 80% of pediatric intensive care unit (PICU) patients experience new morbidities upon discharge. Patients and families rely on clear communication to prepare for post-PICU morbidities.

**Methods** Surveys were given at PICU discharge to parents and attending physicians of patients who developed multi-organ dysfunction within 24 hours of PICU admission and whose parents completed an initial survey 5 to 10 days after PICU admission. Participants were asked about prognostic conversations regarding PICU mortality; patient post-PICU physical, cognitive, and psychological morbidities; and parent post-PICU psychological morbidities. Parents also indicated whether they wanted more prognostic information.

**Results** Forty-nine parents and 20 PICU attending physicians completed surveys for 49 patients. Thirty parent (61%) and 29 physician (59%) surveys reported participating in any prognostic conversations. Concordance between parents and physicians about prognostic conversations was slight ( $\kappa=0.19$ ). Parent ( $n=22$ ; 45%) and physician ( $n=23$ ; 47%) surveys most commonly reported prognostic conversations about post-PICU physical morbidities. Parents less commonly reported conversations about post-PICU cognitive morbidities ( $n=10$ ; 20%). According to parents, bedside nurses and physicians provided most prognostic information; social workers (54%) most commonly discussed parent psychological morbidities. Twenty-six parents (53%) requested more prognostic information.

**Conclusions** Most parents and physicians reported having prognostic conversations, primarily about post-PICU physical morbidities. More than half of parents wanted more information about potential post-PICU morbidities. More research is needed to understand how and when medical professionals should have prognostic conversations with parents. (*American Journal of Critical Care*. 2023;32:118-126)

 **VIDEO ONLINE**

©2023 American Association of Critical-Care Nurses  
doi:<https://doi.org/10.4037/ajcc2023729>

**M**ost pediatric patients survive critical illness, but up to 80% leave the intensive care unit (ICU) with new morbidities.<sup>1,2</sup> Patients and families rely on ICU medical professionals (nurses, physicians, social workers, and others) to discuss the possibility of new morbidities and the risk of mortality and to help them prepare for challenges after discharge.<sup>3</sup> We define these discussions as prognostic conversations.

Post-intensive care syndrome (PICS) describes morbidities related to patient and family physical, cognitive, and psychological outcomes after an ICU stay.<sup>4</sup> Much of what we know about PICS is published in studies of adult patients; literature about PICS in the pediatric population is emerging.<sup>1,5-10</sup> Missing from this pediatric literature is information about how medical professionals talk with patients and families in the pediatric ICU (PICU) about potential outcomes, including PICS. Such prognostic conversations and anticipatory guidance about PICS may help patients and families cope with PICS and empower them to access needed resources.

To date, most research about PICS in pediatric patients has focused on identifying risk factors and common morbidities and evaluating the time to morbidity resolution.<sup>11-13</sup> Fewer studies of prognostic conversations in the PICU related to PICS have been published.<sup>14,15</sup> Previously we described PICU prognostic conversations using parent and attending physician reports 5 to 10 days after a PICU admission.<sup>3</sup> Although important, reports about these conversations early in the PICU stay do not provide information about key conversations that may occur later in the hospitalization.<sup>16</sup> In this article, we describe parent and attending physician reports obtained at the time of a patient's PICU discharge regarding prognostic conversations related to

patient mortality, patient post-PICU morbidities (physical, cognitive, and psychological morbidities), and parent psychological morbidities. We describe the following: (1) prognostic conversation occurrence according to parent and attending physician reports at PICU discharge; (2) concordance between parent and attending physician reports about prognostic conversation occurrence; (3) topics addressed during prognostic conversations, according to parent reports; (4) the medical professionals who provide prognostic information to parents; and (5) parents' interest in receiving more prognostic information.

## Methods

### Setting and Participants

The study took place from September 2019 through August 2020 at a 40-bed quaternary care PICU in Chicago, Illinois. A detailed description of our methods and surveys was published previously.<sup>3</sup> The hospital's institutional review board approved the study with a waiver of signed consent.

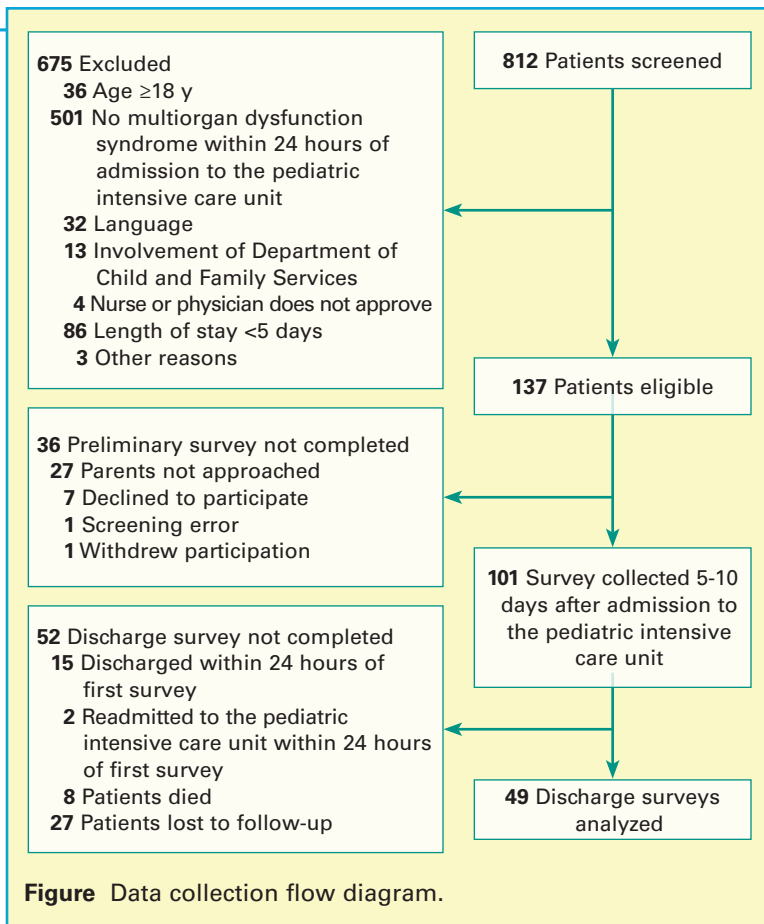
Study participants included parents of PICU patients less than 18 years old who demonstrated multiorgan dysfunction syndrome according to the Goldstein criteria within 24 hours of PICU admission; participating parents also completed an initial survey 5 to 10 days after PICU admission.<sup>17</sup> Parent refers to a biological parent, foster parent, or legal guardian with decision-making authority. One parent per patient was invited to participate. Exclusion criteria for parents were inability to communicate in English or Spanish, participation during a previous PICU stay, indication from a member of the health care team that the parent's participation would be inappropriate, child who died in the PICU, and involvement of the Department of Child and Family Services. We also included the discharging PICU attending physicians caring for the patients whose parents completed surveys.

**This study focuses on conversations pertaining to post-PICU morbidities, what families hear, and what they are hoping to hear more about.**

### About the Authors

**Lauren Rissman** is a pediatric critical care and palliative care physician in the Department of Pediatric Critical Care and Palliative Care, Advocate Children's Hospital, Park Ridge, Illinois. **Sabrina Derrington** is a pediatric critical care physician and bioethicist in the Department of Anesthesiology and Critical Care Medicine, Children's Hospital Los Angeles, California, and in the Department of Pediatrics, Keck School of Medicine, University of Southern California, Los Angeles. **Kelly N. Michelson** is a pediatric critical care physician and bioethicist in the Division of Pediatric Critical Care, Ann and Robert H. Lurie Children's Hospital of Chicago, Illinois, and in the Department of Pediatrics, Northwestern University Feinberg School of Medicine, Chicago.

**Corresponding author:** Lauren Rissman, MD, 1675 Dempster St, Park Ridge, IL 60068 (email: lauren.rissman@aah.org).



### Data Collection

We invited parents to complete a survey at the time of their child’s discharge from the PICU. Surveys (developed as described previously) focused on conversations between health care team members and parents about the patient’s prognosis related to PICU mortality and post-PICU physical, cognitive, and psychological morbidities.<sup>3</sup> Surveys also included demographic information and asked whether the parents had conversations with health care team members about their own post-PICU psychological morbidity. For each topic, we asked parents about the occurrence of prognostic conversations, what was discussed, with whom the discussion occurred, and whether they wanted more information about their child’s prognosis or their

Parents and physicians were surveyed about prognostic conversations and post-PICU morbidities.

own outcomes. Parents who indicated that they talked with the health care team about the possibility that their child might die were also asked if they wanted more information about their child’s possible mortality. Physician surveys, which were sent by email to PICU attending physicians within 24 hours of receiving a

parent survey, included parallel questions related to the same topics. Study surveys (in English and Spanish) were created and administered by using Research Electronic Data Capture (REDCap), a secure web-based application designed to support data capture for research studies.<sup>18</sup> Patient demographic and clinical information was obtained from the electronic medical record.

### Statistical Analysis

We have previously published a full description of our statistical analysis.<sup>3</sup> In brief, we used descriptive statistics to present parent and physician information about reported prognostic conversations for each topic, demographics, clinical information, and whether parents wanted more prognostic information. We used an adapted  $\kappa$  statistic to evaluate concordance between parent and physician reports about the occurrence of prognostic conversations for each topic and any prognostic outcome.

## Results

### Study Participants

During the study period, we screened 812 patients; 137 met the inclusion criteria. Of 110 parents approached for the initial surveys conducted 5 to 10 days after PICU admission, 101 submitted analyzable surveys (initial survey response rate: 92% of parents approached, 74% of parents who met the inclusion criteria) and 49 completed a survey at PICU discharge, a 49% retention rate (see Figure). Complete results of the initial surveys have been published previously.<sup>3</sup> Table 1 shows patient and parent demographics for the initial and discharge surveys. The discharge surveys indicated that most patients were admitted with a respiratory-related diagnosis, had 2-system organ dysfunction, and were transferred to another service in the hospital upon PICU discharge. Parents who completed discharge surveys were most commonly White, Hispanic or Latinx; educated through the high school or college level; and most commonly had an income of less than \$50 000. Notable demographic differences between initial survey and discharge survey demographics were a decrease in the percentage of patients with a new do-not-attempt-to-resuscitate order during the PICU stay (from 12% to 4%) and an increase in the percentage of parents who identified as Hispanic or Latinx (from 34% to 69%).

Twenty PICU attending physicians completed surveys for the 49 patients (some physicians completed surveys for more than 1 patient). Eleven physicians (55%) were female; 7 (35%) had completed fellowship training less than 5 years earlier; 6 (30%) had

completed fellowship training 5 to 10 years earlier; and 7 (35%) had completed fellowship training more than 10 years earlier.

### Parent and Physician Reports of Prognostic Conversations

At PICU discharge, 30 parent surveys (61%) and 29 physician surveys (59%) reported any prognostic conversations. Parent and physician reports of prognostic conversation occurrence for each topic are shown in Table 2. More than 50% of parents reported not having prognostic conversations related to each of the topics. According to parents, most conversations that did occur were regarding post-PICU physical morbidities. Greater than 70% of physician surveys indicated that the physician did not know if conversations related to parent or patient psychological morbidity occurred. More attending physicians than parents reported not knowing about prognostic conversation occurrence.

### Parent and Physician Concordance

Concordance between parents and physicians about reported prognostic conversation occurrence related to any topic was slight ( $\kappa = 0.19$ ; 95% CI,  $-0.16$  to  $0.46$ ). For each outcome, parent and physician concordance was as follows: mortality, 0.15 (95% CI, 0.15-0.43); physical morbidities, 0.06 (95% CI,  $-0.21$  to  $0.28$ ); cognitive morbidities, 0.13 (95% CI,  $-0.13$  to  $0.32$ ); patient psychological morbidities,  $-0.09$  (95% CI,  $-0.23$  to  $0.13$ ); and parent psychological morbidities,  $-0.1$  (95% CI,  $-0.3$  to  $0.13$ ).

### Reports of Conversations on Initial Survey Compared With Discharge Survey

Table 3 shows how parent responses regarding prognostic conversation occurrence changed from the initial survey to the discharge survey. Depending on the topic, 5% to 28% of parents did not recall prognostic conversations that they had previously reported. Of parents who reported no prognostic conversations about patient post-PICU cognitive and psychological morbidities on the initial surveys, 60% and 75% of parents, respectively, noted the occurrence of conversations on these topics on discharge surveys.

### Outcomes Discussed During Prognostic Conversations

The Supplemental Table (available online only at [www.ajconline.org](http://www.ajconline.org)) shows the specific topics discussed during prognostic conversations. This table includes free-text responses from parents who selected "other" and wrote a response.

**Table 1**  
Patient and parent demographics

Demographic feature	No. (%) of responses <sup>a</sup>	
	Initial survey (N = 101)	Discharge survey (N = 49)
<b>Patients</b>		
Sex		
Female	51 (50)	24 (49)
Male	50 (50)	25 (51)
Age, mean (SD), y		
	5.84 (5.9)	4.9 (5.0)
Pediatric Overall Performance Category score on admission		
Good	37 (37)	16 (33)
Mild	18 (18)	9 (18)
Moderate	22 (22)	13 (27)
Severe	20 (20)	10 (20)
Coma/vegetative	4 (4)	1 (2)
Pediatric Overall Performance Category score on discharge <sup>b</sup>		
Good	3 (3)	1 (2)
Mild	16 (16)	7 (14)
Moderate	41 (41)	25 (51)
Severe	25 (25)	15 (31)
Coma/vegetative	4 (4)	1 (2)
Admission diagnosis		
Respiratory	40 (40)	21 (43)
Sepsis	20 (20)	8 (16)
Nontraumatic neurologic	13 (13)	5 (10)
Trauma	5 (5)	3 (6)
Cardiac	5 (5)	3 (6)
Hematologic-oncologic	5 (5)	2 (4)
Electrolyte/fluid	5 (5)	2 (4)
Elective/surgical	8 (8)	5 (10)
Multiorgan dysfunction syndrome criteria, No. of organ systems involved		
2	58 (57)	27 (55)
3	26 (26)	13 (27)
4	11 (11)	5 (10)
5	6 (6)	4 (8)
Course in the pediatric intensive care unit		
Use of continuous renal replacement therapy	11 (11)	5 (10)
Use of extracorporeal membrane oxygenation	3 (3)	1 (2)
New do-not-attempt-resuscitation order >7 days intubation	12 (12)	2 (4)
Pediatric Logistic Organ Dysfunction score in first 24 hours, mean (SD)	37 (37)	21 (43)
	10.8 (6.6)	11 (6.8)
Days in the pediatric intensive care unit, mean (SD)		
	18.5 (18.6)	18.8 (18.8)
Discharge from pediatric intensive care unit to <sup>b</sup>		
Different service in the hospital	67 (66)	39 (80)
Long-term care facility	7 (7)	2 (4)
Home	15 (15)	8 (16)
<b>Parents</b>		
Sex		
Female	75 (74)	36 (73)
Male	25 (25)	13 (27)
Did not disclose	1 (1)	0 (0)
Age, mean (SD), y		
	36.7 (10.4)	36.8 (10.1)

Continued

**Table 1**  
**Continued**

Demographic feature	No. (%) of responses <sup>a</sup>	
	Initial survey (N = 101)	Discharge survey (N = 49)
<b>Parents (continued)</b>		
Race		
Asian or Pacific Islander	13 (13)	8 (16)
Black or African American	17 (17)	6 (12)
White	40 (40)	24 (49)
Other	20 (20)	11 (22)
Did not disclose	11 (11)	0 (0)
Ethnicity		
Non-Hispanic or Latinx	65 (64)	13 (27)
Hispanic or Latinx	34 (34)	34 (69)
Did not disclose	2 (2)	2 (4)
Level of education		
Elementary	3 (3)	0 (0)
High school	44 (44)	19 (39)
Associate's degree	10 (10)	5 (10)
College	25 (25)	15 (31)
Graduate	6 (6)	3 (6)
Postgraduate	12 (12)	6 (12)
Did not disclose	1 (1)	1 (2)
Annual household income, \$		
<50 000	46 (46)	20 (41)
50 000-74 999	14 (14)	7 (14)
75 000-99 000	8 (8)	5 (10)
>100 000	24 (24)	12 (24)
Did not disclose	9 (9)	5 (10)

<sup>a</sup> Unless otherwise indicated.  
<sup>b</sup> Twelve patients died before discharge.

### Medical Professionals Involved in Prognostic Conversations

Table 4 shows data from parent surveys indicating which health care professionals initiated prognostic conversations. Parents reported receiving most prognostic information from physicians or nurse

practitioners; however, parents noted that bedside nurses were more often involved than physicians or nurse practitioners in conversations pertaining to psychological morbidities for the patient and parent. Social workers were the professionals most frequently involved in conversations about parent psychological morbidities.

### Parents' Requests for More Prognostic Information

Twenty-six parents (53%) requested more information about any topic. Table 5 shows parents' responses about wanting more information according to whether they reported that a prognostic conversation occurred. Of the parents who indicated that prognostic conversations about each outcome topic did not occur, 63% reported wanting more information about potential physical morbidities; 46%, cognitive morbidities; and 32%, patient psychological morbidities. For topics that were discussed, 18% to 31% of parents still wanted more prognostic information.

### Discussion

Emerging data about high rates of PICS support the need for pediatric intensivists to engage in prognostic conversations with families.<sup>1,3</sup> This prospective study describes reports about prognostic communication from parents of PICU patients and PICU attending physicians at the time of PICU discharge. We found that only 61% of parents and 59% of physician surveys indicated that prognostic conversations occurred during the PICU stay for patients at high risk of developing PICS. The topic for which parents and physicians reported the most prognostic conversations was patient post-PICU

**Table 2**  
**Outcome topics discussed during prognostic conversations, according to discharge surveys of parents (n=49) and physicians (n=49)**

Outcome topic	No. (%) of responses					
	Yes		No		I don't know	
	Parent	Physician <sup>a</sup>	Parent	Physician <sup>a</sup>	Parent	Physician <sup>a</sup>
Mortality	9 (18)	16 (33)	39 (80)	10 (20)	1 (2)	23 (47)
Patient post-PICU physical morbidities	22 (45)	23 (47)	25 (51)	5 (10)	2 (4)	21 (43)
Patient post-PICU cognitive morbidities	10 (20)	18 (37)	37 (76)	7 (14)	2 (4)	24 (49)
Patient post-PICU psychological morbidities	12 (24)	7 (14)	36 (73)	2 (4)	1 (2)	40 (82)
Parent post-PICU psychological morbidities	13 (27)	11 (22)	35 (71)	3 (6)	1 (2)	35 (71)

Abbreviation: PICU, pediatric intensive care unit.

<sup>a</sup> For physician responses, "Yes" represents either "Yes, I was the one who spoke to the family . . ." or "Yes, someone else spoke to the family . . ." Physician data is based on the number of physician surveys completed. Some physicians completed surveys for more than 1 patient.

**Table 3**  
Changes from initial surveys to discharge surveys in parents' responses regarding conversations about outcome topics

Topic	No. (%) of responses on discharge surveys <sup>a</sup>			
	Yes		No/I don't know	
	Initial survey: yes	Initial survey: no	Initial survey: no	Initial survey: yes
Patient post-PICU physical morbidities	16 (73)	6 (27)	20 (74)	7 (26)
Patient post-PICU cognitive morbidities	4 (40)	6 (60)	34 (87)	5 (13)
Patient post-PICU psychological morbidities	3 (25)	9 (75)	35 (95)	2 (5)
Parent post-PICU psychological morbidities	8 (62)	5 (38)	26 (72)	10 (28)

Abbreviation: PICU, pediatric intensive care unit.

<sup>a</sup> Percentages for yes responses are based on the total number of yes responses for each topic; percentages for no/I don't know responses are based on the total number of no responses for each topic.

**Table 4**  
Professionals involved in prognostic conversations, according to parents' responses on discharge surveys

Professional role	No. (%) of parents' responses on discharge surveys				
	Patient PICU mortality (n=9)	Patient post-PICU physical morbidities (n=22)	Patient post-PICU cognitive morbidities (n=10)	Patient post-PICU psychological morbidities (n=12)	Parent post-PICU psychological morbidities (n=13)
PICU clinician (physician, advanced care practitioner <sup>a</sup> )	7 (78)	15 (68)	8 (80)	7 (58)	3 (23)
Physical therapist	1 (11)	8 (36)	3 (30)	1 (8)	1 (8)
Respiratory therapist	1 (11)	6 (27)	0 (0)	0 (0)	1 (8)
Bedside nurse	1 (11)	8 (36)	5 (50)	8 (67)	6 (45)
Social worker	0 (0)	0 (0)	0 (0)	0 (0)	7 (54)
Case manager	0 (0)	0 (0)	1 (10)	1 (8)	0 (0)
Chaplain	1 (11)	0 (0)	0 (0)	0 (0)	0 (0)
Other	0 (0)	3 (14)	0 (0)	0 (0)	0 (0)
I don't know	1 (11)	2 (9)	1 (10)	0 (0)	1 (8)

Abbreviation: PICU, pediatric intensive care unit.

<sup>a</sup> Refers to intensivists, hospitalists, residents, and nurse practitioners.

**Table 5**  
Parents' requests for more prognostic information according to whether prognostic conversations occurred (per parents' discharge surveys)

Topic	No. (%) of parents	
	Requested more information/ topic not discussed	Requested more information/ topic discussed
Patient post-PICU physical morbidities	17/27 (63)	4/22 (18)
Patient post-PICU cognitive morbidities	18/39 (46)	2/10 (20)
Patient post-PICU psychological morbidities	12/37 (32)	3/12 (25)
Parent post-PICU psychological morbidities	11/36 (31)	4/13 (31)

Abbreviation: PICU, pediatric intensive care unit.

physical morbidities (45% and 47%, respectively). Parents least frequently reported discussions related to mortality (18%) and cognitive morbidities (20%).

Physicians least frequently recalled discussions about patient and parent psychological morbidities (14% and 22% of surveys, respectively). Parents noted

that most prognostic conversations included physicians and nurse practitioners; however, parents reported that bedside nurses often discussed patient psychological morbidities, and bedside nurses and social workers often discussed parent psychological morbidities. Fifty-three percent of parents wanted more prognostic information. Our results highlight opportunities to improve PICU prognostic conversations.

Fewer parents reported prognostic conversations on discharge surveys (61%) than on initial surveys (88%), as reported previously.<sup>3</sup> Although part of this difference may reflect sampling bias, some of this difference reflects a change in parent report. Depending on the topic, up to 28% of parents who had reported a prognostic conversation occurrence earlier in the PICU stay indicated at discharge that either those conversations had not occurred or that

they did not remember them. Additionally, some parents who had received prognostic information wanted more information. Experts describe the importance of repeating information over multiple conversations, particularly when talking with patients or families in stressful situations. Providing information in multiple formats

helps meet the diverse needs of parents with varied learning styles.<sup>19-21</sup> These findings underscore the need to repeat information. Currently, no protocol exists to guide prognostic conversations with families; future work should include creating and evaluating such a communication protocol. These data also highlight the importance of revisiting previous conversations with parents if relevant for the patient or family or at least asking parents if they would like more information about a relevant topic.

Some parents who reported prognostic conversations at the time of discharge did not report these conversations on the initial surveys. This result may reflect parents underreporting conversations 5 to 10 days after admission (further reinforcing the need to repeat information) or parents reporting conversations that occurred later during the PICU stay. No rules or recommendations guide when such conversations

should occur. In many cases, clinicians may wait to have prognostic conversations because they do not anticipate serious morbidities or they do not have enough information to provide meaningful predictions. However, previous data show that parents want more prognostic information, even early in a PICU stay.<sup>3</sup> The parents' expressed desire for more prognostic information suggests that research is needed to better understand when clinicians should communicate information about prognosis to parents.

Parents' desire for more prognostic information is reflected in our finding that 53% of parents requested more information about some topic. Parents requesting more information is a ubiquitous finding in studies of pediatric patients regarding prognosis discussions and difficult conversations, highlighting that clear communication helps alleviate parental anxiety.<sup>22-27</sup> We posit multiple explanations for why clinicians may not engage in prognostic conversations: prognostic uncertainty, discomfort in communicating prognosis, inadequate training in prognostic communication, and perception that the patient's clinical trajectory does not warrant such discussions. Knowledge about the prevalence of PICS is mostly related to physical morbidities<sup>3,9</sup> and is still emerging, making it challenging for clinicians to prognosticate. This situation may explain why parents most commonly reported they had prognostic conversations about patients' physical morbidities. As more information about PICS becomes available and enhances clinicians' ability to prognosticate, understanding barriers to clinician engagement in prognostic conversations with parents will become increasingly important.

Other key findings included the following: (1) most surveys of attending physicians indicated that they did not know whether prognostic conversations occurred, (2) concordance between parent and physician surveys was poor, and (3) bedside nurses and social workers were more likely than other medical professionals to discuss psychological morbidities. These findings suggest opportunities and a need to improve team communication. Medical professionals in the PICU are a multidisciplinary group of clinicians who change frequently, introducing challenges to team communication.<sup>3,28</sup> At the institution where this study took place, attending physicians and fellows rotate at least once per week, and advanced practice nurses and bedside nurses rotate more frequently. Information sharing among clinicians from different disciplines is also not consistent; for example, social workers or bedside nurses may not convey all information about their communication with families

**Future studies could evaluate how families wish to receive information, how they interpret prognostic statements, and what information they wish they had received in the PICU months after transitioning to home.**

to other team members and vice versa. Medical professionals in the PICU need better approaches for sharing information among the multidisciplinary team about prognostic conversations with parents. Documentation in the medical record can support this goal, but relying on the medical record for multidisciplinary communication may not be the most efficient and effective approach. Another approach is to introduce a program like pediatric ethics and communication excellence rounds, which are weekly meetings to identify and share goals of care for children with prolonged PICU stays. A study of pediatric ethics and communication excellence rounds at a single center showed improved perceptions of team communication, decreased moral distress among clinicians, and shorter stays.<sup>29</sup>

Results of this work should be viewed in the context of its strengths and limitations. One strength is that we collected information at PICU discharge, reflecting prognostic conversations that occurred throughout the PICU stay. However, because information was collected at discharge, our data may be subject to recall bias because the average PICU stay was almost 3 weeks. Additionally, we did not evaluate parents' sense of preparedness for post-ICU morbidities. In future studies, researchers should evaluate family preparedness at and after discharge to compare expectations with reality. We administered the survey only to each patient's attending physician at the time of discharge and thus cannot comment on other health care providers' knowledge about prognostic conversations. Future studies should address prognostic conversations at the time they occurred from the perspectives of clinicians, families, and the multidisciplinary team. Our data are also subject to response bias because only 49% of parents who completed an initial survey 5 to 10 days after PICU admission also completed the PICU discharge survey. Reasons for attrition may include hospital COVID-19 restrictions limiting researchers' ability to engage with families, survey length, repeated survey administration, or inadequate incentive. Responses to our question about whether parents wanted more prognostic information could be subject to confirmation bias; however, the varied responses to each topic potentially suggest otherwise. Future studies should retrospectively evaluate the accuracy of prognostic discussions and whether families wished they had received information differently after the patient was discharged from the PICU. Our sample size was small and included parents and physicians at only 1 hospital, potentially impacting generalizability. However, the group of parents who

participated was diverse with respect to race, ethnicity, education, and income. We also did not clarify where families received information (daily rounds, family conferences, or another source).

## Conclusions

At discharge, approximately 60% of parent and physician surveys indicated that prognostic conversations about any topic occurred, with only slight concordance. Most parents recalled conversations about post-PICU physical morbidities. Fifty-three percent of parents requested more prognostic information about some topic. The findings of this study suggest that recommendations for improving prognostic conversations should include how information is provided (and the need to repeat information), when information is provided, and how to enhance team communication about conversations with patients and their families.

## FINANCIAL DISCLOSURES

Funding was provided by a Northwestern University Center for Bioethics and Medical Humanities Research Pilot/Exploratory Grant.

## REFERENCES

1. Hartman ME, Williams CN, Hall TA, Bosworth CC, Piantino JA. Post-intensive-care syndrome for the pediatric neurologist. *Pediatr Neurol*. 2020;108:47-53. doi:10.1016/j.pediatrneurol.2020.02.003
2. 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. doi:10.1097/PCC.0000000000001070
3. Rissman L, Derrington S, Rychlik K, Michelson KN. Parent and physician report of discussions about prognosis for critically ill children. *Pediatr Crit Care Med*. 2021;22(9):785-794. doi:10.1097/pcc.0000000000002764
4. 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. doi:10.1097/PCC.0000000000001476
5. Rousseau AF, Prescott HC, Brett SJ, et al. Long-term outcomes after critical illness: recent insights. *Crit Care*. 2021;25(1):108. doi:10.1186/s13054-021-03535-3
6. Yanagi N, Kamiya K, Hamazaki N, et al. Post-intensive care syndrome as a predictor of mortality in patients with critical illness: a cohort study. *PLoS One*. 2021;16(3):e0244564. doi:10.1371/journal.pone.0244564
7. Miyamoto K, Shibata M, Shima N, et al; W-PICS Investigators. Combination of delirium and coma predicts psychiatric symptoms at twelve months in critically ill patients: a longitudinal cohort study. *J Crit Care*. 2021;63:76-82. doi:10.1016/j.jccr.2021.01.007
8. Morgan A. Long-term outcomes from critical care. *Surgery (Oxf)*. 2021;39(1):53-57. doi:10.1016/j.mpsur.2020.11.005
9. 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. doi:10.1016/j.jpeds.2017.12.084
10. Chaiyakuil S, Opasatian R, Tippayawong P. Pediatric postintensive care syndrome: high burden and a gap in evaluation tools for limited-resource settings. *Clin Exp Pediatr*. 2021;64(9):436-442. doi:10.3345/cep.2020.01354
11. Woodruff AG, Choong K. Long-term outcomes and the post-intensive care syndrome in critically ill children: a North American perspective. *Children (Basel)*. 2021;8(4):254. doi:10.3390/children8040254
12. Ghafoor S, Fan K, Williams S, et al. Beginning restorative activities very early: implementation of an early mobility



- initiative in a pediatric onco-critical care unit. *Front Oncol*. 2021;11:645716. doi:10.3389/fonc.2021.645716
13. Flaws D, Manning JC. Post intensive care syndrome across the life course: looking to the future of paediatric and adult critical care survivorship. *Nurs Crit Care*. 2021;26(2):64-66. doi:10.1111/nicc.12605
  14. Rossfeld ZM, Miller R, Tumin D, Tobias JD, Humphrey LM. Implications of pediatric palliative consultation for intensive care unit stay. *J Palliat Med*. 2019;22(7):790-796. doi:10.1089/jpm.2018.0292
  15. Rothschild CB, Derrington SF. Palliative care for pediatric intensive care patients and families. *Curr Opin Pediatr*. 2020;32(3):428-435. doi:10.1097/MOP.0000000000000903
  16. Spraker-Perlman HL, Tam RP, Bardsley T, et al. The impact of pediatric palliative care involvement in the care of critically ill patients without complex chronic conditions. *J Palliat Med*. 2019;22(5):553-556. doi:10.1089/jpm.2018.0469
  17. Goldstein B, Giroir B, Randolph A. International pediatric sepsis consensus conference: definitions for sepsis and organ dysfunction in pediatrics. *Pediatr Crit Care Med*. 2005;6(1):2-8. doi:10.1097/01.PCC.0000149131.72248.E6
  18. Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research Electronic Data Capture (REDCap): a metadata-driven methodology and workflow process for providing translational research informatics support. *J Biomed Inform*. 2009;42(2):377-381. doi:10.1016/j.jbi.2008.08.010
  19. VandeKieft GK. Breaking bad news. *Am Fam Physician*. 2001;64(12):1975-1978.
  20. Hanratty B, Lawson E, Holmes L, et al. Breaking bad news sensitively: what is important to patients in their last year of life? *BMJ Support Palliat Care*. 2012;2(1):24-28. doi:10.1136/bmjspcare-2011-000084
  21. Brouwer MA, Maeckelberghe ELM, van der Heide A, Hein IM, Verhagen EAAE. Breaking bad news: what parents would like you to know. *Arch Dis Child*. 2021;106(3):276-281. doi:10.1136/archdischild-2019-318398
  22. Mack JW, Joffe S. Communicating about prognosis: ethical responsibilities of pediatricians and parents. *Pediatrics*. 2014;133 Suppl 1:S24-S30. doi:10.1542/peds.2013-3608e
  23. Sisk BA, Kang TI, Mack JW. Prognostic disclosures over time: parental preferences and physician practices. *Cancer*. 2017;123(20):4031-4038. doi:10.1002/cncr.30716
  24. Meert KL, Eggly S, Pollack M, et al. Parents' perspectives on physician-parent communication near the time of a child's death in the pediatric intensive care unit. *Pediatr Crit Care Med*. 2008;9(1):2-7. doi:10.1097/01.PCC.0000298644.13882.88
  25. Needle JS, O'Riordan M, Smith PG. Parental anxiety and medical comprehension within 24 hrs of a child's admission to the pediatric intensive care unit. *Pediatr Crit Care Med*. 2009;10(6):668-674; quiz 674. doi:10.1097/PCC.0b013e3181a706c9
  26. Rennie JE, St-Sauveur I, Knox AM, Ruddy M. Exploring the experiences of parent caregivers of children with chronic medical complexity during pediatric intensive care unit hospitalization: an interpretive descriptive study. *BMC Pediatr*. 2019;19(1):272. doi:10.1186/s12887-019-1634-0
  27. October TW, Dizon ZB, Arnold RM, Rosenberg AR. Characteristics of physician empathetic statements during pediatric intensive care conferences with family members: a qualitative study. *JAMA Netw Open*. 2018;1(3):e180351. doi:10.1001/jamanetworkopen.2018.0351
  28. Trevick S, Kim M, Naidech A. Communication, leadership, and decision-making in the neuro-ICU. *Curr Neurol Neurosci Rep*. 2016;16(11):99. doi:10.1007/s11910-016-0699-5
  29. Wocial L, Ackerman V, Leland B, et al. Pediatric ethics and communication excellence (PEACE) rounds: decreasing moral distress and patient length of stay in the PICU. *HEC Forum*. 2017;29(1):75-91. doi:10.1007/s10730-016-9313-0

To purchase electronic or print reprints, contact American Association of Critical-Care Nurses, 27071 Aliso Creek Road, Aliso Viejo, CA 92656. Phone, (800) 899-1712 or (949) 362-2050 (ext 532); fax, (949) 362-2049; email, reprints@aacn.org.

**Supplemental Table**  
**Outcomes discussed during prognostic conversations,**  
**according to parents' discharge surveys**

Outcome topic (No. of surveys)	Outcomes discussed	No. (%) of parent responses
Patient post-PICU physical morbidities (22)	New home technology <sup>a</sup>	13 (59)
	Changes in everyday activities <sup>b</sup>	11 (50)
	Other	5 (23)
Patient post-PICU cognitive morbidities (10)	Thinking	5 (50)
	Memory	4 (40)
	Learning	5 (50)
	Seizures	2 (20)
	Other <sup>c</sup>	4 (40)
Patient post-PICU psychological morbidities (12)	Anxiety	6 (50)
	Depression	3 (25)
	Sleeping	8 (67)
	Behavior changes	3 (25)
	Posttraumatic stress disorder	3 (25)
	Other <sup>d</sup>	2 (17)
Parent post-PICU psychological morbidities (13)	Anxiety	8 (62)
	Depression	8 (62)
	Sleeping changes	9 (69)
	Posttraumatic stress disorder	4 (31)
	Other <sup>e</sup>	2 (15)

Abbreviation: PICU, pediatric intensive care unit.

<sup>a</sup> A new respiratory device (n=8), feeding device (n=5), and dialysis (n=1).

<sup>b</sup> Feeding (n=8), muscle weakness (n=10), walking (n=6), balance (n=8), seeing (n=3), and hearing (n=2).

<sup>c</sup> "We were assured she was NOT having seizures and therefore was not having an adverse effect on her brain," "Behavioral," "Delirium, disorientation."

<sup>d</sup> "Possible delirium from being in the PICU for a long period of time" and "Anxiety over returning . . . for routine appointments."

<sup>e</sup> "Having gone through a code with my son, I would get upset every time I heard it and saw everybody running. I would worry about that child and family. I would get anxious. I also don't leave his bedside at all and the nurse and staff always checking on me—how I'm feeling and making sure I ate" and "posttraumatic stress."