Limiting and Withdrawing Life Support in the PICU: For Whom Are These Options Discussed?*

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The study was supported by the following cooperative agreements from the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development, National Institutes of Health, Department of Health and Human Services: grant U10HD050096, U10HD049981, U10HD063108, U10HD063106, U10HD063114, U10HD049983, U10HD050012, and U01HD049934.

Dr. Meert received support for article research from the National Institutes of Health (NIH). Her institution received grant support from the NIH. Dr. Keele is employed by the Pediatric Anesthesia Associates Medical Group. Dr. Berg received support for article research from the NIH. His institution received grant support from the NICHD. Dr. Dalton received royalties from SCCM (book author royalties), received support for article research from the NIH, consulted for Innovative ECMO Concepts, consulted for Innovative ECMO Concepts, is employed by Alaskan Native Tribal Health Center, and lectured for Maquet Inc. Her institution received grant support and support for travel from the NIH. Dr. Newth received support for article research from the NIH. His institution received grant support from the NIH. Dr. Harrison received support for article research from the NIH. His institution received grant support from the NIH and received support for travel from the SCCM (for lectures). Dr. Wessel received support for article research from the NIH. His institution received grant support from the NIH. Dr. Shanley provided expert testimony for Clore and Assoc's (legal case review); received royalties from Springer (textbook royalties); served as a board member for Univ MN, Case Western (served on EAB's); and received support for article research from the NIH. His institution received grant support and support for travel from the NIH. Dr. Carcillo received support for article research from the NIH. His institution received grant support. Dr. Morrison consulted for Glaxo-Smith-Klein (Data monitoring committee) and received support for travel from Grand rounds (speaker at several academic institutions). Dr. Funai received support for article research from the NIH. Dr. Funai and his institution received grant support from the NIH (Salary support as Biostatistician). Dr. Holubkov received support for article research from the NIH and served as a board member for Pfizer, Inc. (DSMB Board Member); Inno Clinical Outcomes LLC (DSMB Board Member); and Armaron Bio PTY Limited (Australia) (DSMB Board Member). He consulted for Physicians Committee for Responsible Medicine (Biostatistical Consultant) and St. Jude Medical, Inc. (Biostatistical Consultant). Dr. Holubkov and his institution received grant support and support for travel from the NIH/NICHD (Grant also pays for CPCCRN network meetings). Dr. Dean received support for article research from the NIH. His institution received grant support from the NIH. Dr. Pollack consulted (Medical legal consultation), lectured (occasional honoraria for academic talks), and received support for article research from the NIH. His institution has patents (no money, but patents are pending with Children's National Health System and Phoenix Children's Hospital) and received grant support (research funded by grants) and support for travel.

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DOI: 10.1097/PCC.0000000000000614

Objectives: Most deaths in U.S. PICUs occur after a decision has been made to limitation or withdrawal of life support. The objective of this study was to describe the clinical characteristics and outcomes of children whose families discussed limitation or withdrawal of life support with clinicians during their child's PICU stay and to determine the factors associated with limitation or withdrawal of life support discussions.

Design: Secondary analysis of data prospectively collected from a random sample of children admitted to PICUs affiliated with the Collaborative Pediatric Critical Care Research Network between December 4, 2011, and April 7, 2013.

Setting: Seven clinical sites affiliated with the Collaborative Pediatric Critical Care Research Network.

Patients: Ten thousand seventy-eight children less than 18 years old, admitted to a PICU, and not moribund at admission.

Interventions: None.

Measurements and Main Results: Families of 248 children (2.5%) discussed limitation or withdrawal of life support with clinicians.

By using a multivariate logistic model, we found that PICU admission age less than 14 days, reduced functional status prior to hospital admission, primary diagnosis of cancer, recent catastrophic event, emergent PICU admission, greater physiologic instability, and government insurance were independently associated with higher likelihood of discussing limitation or withdrawal of life support. Black race, primary diagnosis of neurologic illness, and postoperative status were independently associated with lower likelihood of discussing limitation or withdrawal of life support. Clinical site was also independently associated with likelihood of limitation or withdrawal of life support discussions. One hundred seventy-three children (69.8%) whose families discussed limitation or withdrawal of life support died during their hospitalization; of these, 166 (96.0%) died in the PICU and 149 (86.1%) after limitation or withdrawal of life support was performed. Of those who survived, 40 children (53.4%) were discharged with severe or very severe functional abnormalities, and 15 (20%) with coma/vegetative state.

Conclusions: Clinical factors reflecting type and severity of illness, sociodemographics, and institutional practices may influence whether limitation or withdrawal of life support is discussed with families of PICU patients. Most children whose families discuss limitation or withdrawal of life support die during their PICU stay; survivors often have substantial disabilities. (*Pediatr Crit Care Med* 2016; 17:110–120)

Key Words: children; death; decision making; infants; PICU

Due to improved utilization of Palliative Care and Hospice Services over the past decade, more terminally ill children are dying at home (1). However, most childhood deaths in the United States and other developed countries still occur in hospital settings (2–4). Among children who die in hospitals, over 60% die in PICUs (1, 5). Pediatric intensivists are often responsible for discussing end-of-life options with families including the option of limitation or withdrawal of life support (LWLS). LWLS refers to withholding or withdrawing life-sustaining therapies, respectively, with death as the expected outcome. Over two thirds of deaths in U.S. PICUs occur after a decision has been made to limit or withdraw support (6, 7).

Prior studies have evaluated the content and quality of ICU family conferences in which LWLS was discussed (8–13). Recommendations and guidelines for improving clinician-family communication during LWLS discussions have also been developed (14–16). However, the characteristics and outcomes of children whose families discuss LWLS with clinicians have not been well described. Since discussions about LWLS are most often initiated by clinicians (17), knowledge about the characteristics of children whose families participate in these discussions may provide insight into the factors that prompt clinicians to consider LWLS. Clinicians may recognize certain patient characteristics as morbid suggesting a need for comfort rather than curative care. The objective of this study was to describe the clinical characteristics and outcomes of children whose families discussed LWLS with clinicians during their child's PICU stay and to determine the factors associated with LWLS discussions.

MATERIALS AND METHODS

Design and Setting

The study was a secondary analysis of data prospectively collected from a random sample of children ($n = 10,078$) admitted to PICUs affiliated with the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development Collaborative Pediatric Critical Care Research Network (CPCCRN) between December 4, 2011, and April 7, 2013 (18). The CPCCRN includes seven clinical sites, which have approximately 17,000 PICU admissions each year, and a data coordinating center (19, 20). Each clinical site enrolled 12–16% of the sample. The study was approved by the institutional review board at each site and the data coordinating center. The requirements for parental permission and child assent were waived.

Study Population

Children were eligible for inclusion if they were less than 18 years old and admitted to a PICU. Children were excluded if they had a previous PICU admission during the current hospitalization or if their vital signs were incompatible with life for at least the first 2 hours after PICU admission (i.e., moribund children).

Data Collection

The primary outcome variable for this analysis was whether or not the child's family participated in a discussion about LWLS with clinicians during their child's PICU stay. The primary outcome was determined by trained research assistants through prospective record review, direct observation, and discussion with bedside clinicians (18). Research assistants typically worked daytime hours and were not in the PICU continuously. Families were not queried as to recollection of a discussion about LWLS.

Other variables included child sociodemographics such as age, sex, race/ethnicity, and primary payer type. Race and ethnicity are not differentiated in the medical records of all CPCCRN sites; therefore, a single variable (i.e., race/ethnicity) was used. Hispanic ethnicity alone or with any race designation was categorized as Hispanic. Non-Hispanic (NH) ethnicity was further categorized into one of the several race designations: American Indian or Alaska native, Asian, black or African American, native Hawaiian or other pacific islander, white, multiracial, and unknown or not reported. Other variables included primary and secondary PICU admission diagnoses, presence of chronic illness, history of developmental delay, baseline functional and cognitive status prior to hospital admission, occurrence of a catastrophic event between 24 hours prior to hospital admission and PICU admission, worst Glasgow Coma Scale (GCS) (21) score and level of consciousness (i.e., coma vs no coma) between 0 and 4 hours after PICU admission, Pediatric Risk of Mortality III (PRISM III) (22) score, PICU admission status (i.e., elective vs emergency),

type of PICU (i.e., general medical/surgical, cardiac/cardiovascular, or other), admission to PICU postoperatively, type of clinical service with primary responsibility (i.e., medical, cardiovascular surgery, or other surgical service), and clinical site.

Baseline functional and cognitive status were assessed by using the Functional Status Scale (FSS) (23), the Pediatric Overall Performance Category (POPC), and Pediatric Cerebral Performance Category (PCPC) scales (24). FSS is an objective scale for assessing functional status in six domains including mental, sensory, communication, motor function, feeding, and respiratory status (23). Total FSS scores range from 6 to 30 and are categorized as 6–7 (good), 8–9 (mildly abnormal), 10–15 (moderately abnormal), 16–21 (severely abnormal), and greater than 21 (very severely abnormal). POPC and PCPC are subjective scales for assessing overall functional morbidity and cognitive impairment, respectively (24). Both are 6-point graded scales of increasing disability. Scores are 1 for good/normal, 2 for mild disability, 3 for moderate disability, 4 for severe disability, 5 for coma or vegetative state, and 6 for death. GCS is a scale developed for assessing level of consciousness after traumatic brain injury and ranges from 3 to 15 with higher scores indicating a higher level of consciousness (21). PRISM III is a scale for assessing physiologic instability of PICU patients and ranges from 0 to 74 with higher scores indicating a greater degree of physiologic instability (22). PRISM III scores were determined from patient data obtained 2 hours prior to PICU admission through 4 hours post-PICU admission (25).

The timing of PRISM III assessment and other related variables for cardiac patients less than 3 months of age was adjusted because at some sites, infants are admitted to the PICU prior to a cardiac intervention to optimize clinical status but not for intensive care. In such cases, the postoperative period was used instead of the PICU admission period to assess the PRISM III since it more accurately reflects intensive care (18). This adjustment was operationalized in other variables as well. For example, instead of age at PICU admission, the age at return from cardiac intervention was used for these young cardiac patients. Likewise, the timing for occurrence of a catastrophic event was modified to between 24 hours prior to hospital admission and return from cardiac intervention, instead of between 24 hours prior to hospital admission and PICU admission. Furthermore, we needed to operationalize the FSS scores for newborn patients who never achieved stable baseline function; these patients were assigned a baseline FSS score of 6 (18).

Variables related to patient disposition included hospital mortality and discharge FSS (23) and POPC and PCPC scores (24). For children who died, additional variables included location of death, mode of death, and length of hospital stay. Location of death included PICU, general ward, or other hospital location. Mode of death included failed resuscitation, limitation of support, withdrawal of support, or brain death. For children who survived, additional variables included discharge location and whether the patient was discharged from the hospital with hospice services. Discharge location included home or foster care, another acute care hospital, acute inpatient rehabilitation unit, chronic care/skilled nursing facility, or other location.

Statistical Analysis

Distributions of variables were described for children whose families discussed LWLS and those whose families did not using counts and percentages for categorical variables and medians, first quartiles, and third quartiles for continuous variables. Association of each variable with whether or not LWLS was discussed was examined using chi-square or Fisher exact tests for binary/unordered categorical variables, the Cochran-Armitage test for trend for ordered categorical variables, and the Wilcoxon rank sum test for continuous variables.

Multivariable logistic regression was used to obtain adjusted odds ratios for covariates associated with family participation in an LWLS discussion. Candidate covariates were identified as those clinically relevant to the outcome; baseline FSS score was selected as the most clinically appropriate summary of the child's neurologic status at admission. All candidate covariates showing association ($p < 0.10$) in univariate models were entered into an initial multivariable model, and those exhibiting association (adjusted $p < 0.10$) with the outcome using a forward stepwise selection algorithm were kept in the final model. The Hosmer-Lemeshow test was used to evaluate the overall model goodness of fit. All statistical analyses were performed in SAS version 9.4 (SAS Institute, Cary, NC).

RESULTS

Of the 10,078 children included in the study, 248 (2.5%) had families that discussed LWLS with clinicians during their child's PICU stay. Sociodemographics of children whose families did and did not discuss LWLS are shown in **Table 1**. No difference was observed in child gender between groups. Children whose families discussed LWLS were more likely to be younger than 14 days old ($p < 0.001$), more likely to be Hispanic, less likely to be NH black or NH white ($p < 0.001$), and more likely to have government insurance ($p < 0.001$) than those whose families did not discuss LWLS. Clinical site was also associated with the likelihood of LWLS discussions ($p < 0.001$).

Clinical characteristics present on PICU admission for children whose families did and did not discuss LWLS with clinicians are shown in **Table 2**. Children whose families discussed LWLS were more likely to have a primary diagnosis of acquired cardiovascular disease ($p < 0.001$), chronic illness ($p = 0.01$), and a history of developmental delay ($p < 0.001$) than those whose families did not discuss LWLS. Children whose families discussed LWLS had reduced baseline functional and cognitive status prior to hospital admission as assessed by FSS ($p < 0.001$), POPC ($p < 0.001$), and PCPC ($p < 0.001$) scores. Children whose families discussed LWLS were more likely to have had a catastrophic event between 24 hours prior to hospital admission and PICU admission ($p < 0.001$), lower GCS scores ($p < 0.001$), and level of consciousness ($p < 0.001$) 0–4 hours after PICU admission and higher PRISM III scores ($p < 0.001$). Children whose families discussed LWLS were more likely to be admitted to the PICU emergently ($p < 0.001$) and to a medical service ($p < 0.001$) and less likely to be admitted postoperatively ($p < 0.001$).

TABLE 1. Sociodemographics of Children Whose Families Did and Did Not Discuss Limitation or Withdrawal of Life Support With Clinicians

Sociodemographics	Did Not Have Discussions *n* = 9,830 *n* (%)	Had Discussions *n* = 248 *n* (%)	*p*[a]
Gender			0.193
Male	5,404 (55.0)	126 (50.8)	
Female	4,426 (45.0)	122 (49.2)	
Age at PICU admission			< 0.001
0 d to < 14 d	455 (4.6)	37 (14.9)	
14 d to < 1 mo	137 (1.4)	1 (0.4)	
1 mo to < 12 mo	2,111 (21.5)	53 (21.4)	
> 12 mo	7, 127 (72.5)	157 (63.3)	
Race/ethnicity			< 0.001
Hispanic	1,656 (16.8)	70 (28.2)	
American Indian or Alaska Native, NH	135 (1.4)	7 (2.8)	
Asian, NH	253 (2.6)	10 (4.0)	
Black or African American, NH	2,231 (22.7)	40 (16.1)	
Native Hawaiian or other Pacific Islander, NH	34 (0.3)	2 (0.8)	
White, NH	4,622 (47.0)	89 (35.9)	
Multiracial, NH	14 (0.1)	0 (0)	
Unknown or not reported	885 (9.0)	30 (12.1)	
Payer type			< 0.001
Government	5,248 (53.4)	172 (69.4)	
Nongovernment	4,358 (44.3)	70 (28.2)	
Missing	224 (2.3)	6 (2.4)	
Site			< 0.001
1	1,373 (14.0)	31 (12.5)	
2	1,583 (16.1)	34 (13.7)	
3	1,215 (12.4)	37 (14.9)	
4	1,345 (13.7)	68 (27.4)	
5	1,469 (14.9)	29 (11.7)	
6	1,511 (15.4)	36 (14.5)	
7	1,334 (13.6)	13 (5.2)	

NH = non-Hispanic.
[a]*p* value reflects the Cochran-Armitage test for the age at PICU admission and the χ^2 or Fisher exact test for all other variables.

Sociodemographic and clinical characteristics independently associated with family participation in a discussion about LWLS are shown in **Table 3**. Age younger than 14 days at PICU admission, worse baseline FSS score, primary diagnosis of cancer, catastrophic event between 24 hours prior to hospital admission and PICU admission, emergent PICU admission, higher PRISM III score, and government insurance were independently associated with greater likelihood of discussing LWLS. NH black race, primary diagnosis of a neurologic or miscellaneous condition, and postoperative status were independently associated with lower likelihood of discussing LWLS. Clinical site was also independently associated with the likelihood of LWLS discussions ($p < 0.001$). Several of the postadjustment associations in Table 3 are stronger than the univariate distributions observed in

Table 2. Although approximately 4% of children in groups discussing and not discussing LWLS had cancer as a primary diagnosis, odds of having a discussion for children with cancer are over three-fold higher after adjustment for other factors. Although the group who had discussions had only a somewhat smaller proportion of NH black children than those not having discussions, the adjusted odds of families of NH black children having discussion are less than one half that of NH white children's families.

TABLE 2. Clinical Characteristics at PICU Admission for Children Whose Families Did and Did Not Discuss Limitation or Withdrawal of Life Support With Clinicians

Clinical Characteristics	Did Not Have Discussions *n* = 9,830 *n* (%)	Had Discussions *n* = 248 *n* (%)	*p*[a]
Primary diagnosis			< 0.001
Respiratory	3,285 (33.4)	91 (36.7)	
Cancer	359 (3.7)	11 (4.4)	
Cardiovascular (acquired)	624 (6.3)	49 (19.8)	
Cardiovascular (congenital)	1,706 (17.4)	51 (20.6)	
Neurologic	1,987 (20.2)	35 (14.1)	
Miscellaneous[b]	1,869 (19.0)	11 (4.4)	
Primary or secondary diagnosis of trauma	635 (6.5)	15 (6.0)	0.795
Chronic diagnoses at admission	7,213 (73.4)	201 (81.0)	0.01
Known developmental delay	2,373 (24.1)	98 (39.5)	< 0.001
Baseline Functional Status Scale			< 0.001
Good (6, 7)	7,099 (72.2)	134 (54.0)	
Mildly abnormal (8, 9)	996 (10.1)	28 (11.3)	
Moderately abnormal (10–15)	1,216 (12.4)	53 (21.4)	
Severely abnormal (16–21)	397 (4.0)	20 (8.1)	
Very severely abnormal (> 21)	122 (1.2)	13 (5.2)	
Baseline Pediatric Overall Performance Category			< 0.001
Good	3,847 (39.1)	69 (27.8)	
Mild disability	3,170 (32.2)	41 (16.5)	
Moderate disability	1,818 (18.5)	59 (23.8)	
Severe disability	899 (9.1)	71 (28.6)	
Coma/vegetative	96 (1.0)	8 (3.2)	
Baseline Pediatric Cerebral Performance Category			< 0.001
Normal	6,827 (69.5)	132 (53.2)	
Mild disability	1,547 (15.7)	33 (13.3)	
Moderate disability	732 (7.4)	27 (10.9)	
Severe disability	631 (6.4)	48 (19.4)	
Coma/vegetative	93 (0.9)	8 (3.2)	
Worst Glasgow Coma Scale			< 0.001
8–15	9,261 (94.2)	163 (65.7)	
3–7	565 (5.7)	85 (34.3)	
Unable to assess	4 (0)	0 (0)	

(*Continued*)

TABLE 2. (*Continued*). Clinical Characteristics at PICU Admission for Children Whose Families Did and Did Not Discuss Limitation or Withdrawal of Life Support With Clinicians

Clinical Characteristics	Did Not Have Discussions *n* = 9,830 *n* (%)	Had Discussions *n* = 248 *n* (%)	*p*[a]
Level of consciousness			< 0.001
No coma	8,412 (85.6)	118 (47.6)	
Coma	344 (3.5)	70 (28.2)	
Unable to assess	1,071 (10.9)	60 (24.2)	
Missing	3 (0)	0 (0)	
Pediatric Risk of Mortality score			< 0.001
Median (first quartile, third quartile)	2 (0, 5)	11 (4, 19.5)	
PICU admission status			< 0.001
Elective	3,636 (37.0)	31 (12.5)	
Emergency	6,194 (63.0)	217 (87.5)	
Type of PICU admitted to			0.364
Medical/surgical	7,926 (80.6)	193 (77.8)	
Cardiac/cardiovascular	1,876 (19.1)	55 (22.2)	
Other	23 (0.2)	0 (0)	
Unknown	5 (0.1)	0 (0)	
Admitted postoperatively to PICU	3,759 (38.2)	38 (15.3)	< 0.001
Any catastrophic event between 24 hr prior to hospital admission and PICU admission[c]	379 (3.9)	63 (25.4)	< 0.001
Specific types of catastrophic event between 24 hr prior to hospital admission and PICU admission[d]			
Hypoxic ischemic encephalopathy	4 (0)	5 (2.0)	
Cardiac arrest	97 (1.0)	44 (17.7)	
Respiratory arrest	88 (0.9)	11 (4.4)	
Traumatic brain injury	137 (1.4)	13 (5.2)	
Spinal cord injury	6 (0.1)	1 (0.4)	
Stroke	21 (0.2)	0 (0)	
Other catastrophic event	41 (0.4)	1 (0.4)	
Clinical service with primary responsibility			< 0.001
Medical	7,750 (78.8)	231 (93.1)	
Cardiovascular surgical	470 (4.8)	6 (2.4)	
Other surgical	1,610 (16.4)	11 (4.4)	

[a]*p* value reflects the Wilcoxon rank sum test for Pediatric Risk of Mortality III, Cochran-Armitage test for baseline Functional Status Scale, baseline Pediatric Overall Performance Category, and baseline Pediatric Cerebral Performance Category and the χ^2 or Fisher exact test for all other variables.

[b]Includes diabetic ketoacidosis, musculoskeletal condition, gastrointestinal disorder, hematologic disorder, renal, and miscellaneous.

[c]Number and proportion of children who experienced any catastrophic events between 24 hr prior to hospital admission and PICU admission.

[d]Number and proportion of children who experienced the specific type of catastrophic event; an individual child could experience more than one type of catastrophic event.

TABLE 3. Adjusted Odds Ratios for Family Discussion Participation for Sociodemographic and Clinical Characteristics

Characteristics	OR (95% CI)
Age at PICU admission	
0 d to < 14 d	3.18 (1.69–5.97)
14 d to < 1 mo	0.42 (0.06–3.17)
1 mo to < 12 mo	0.98 (0.67–1.43)
> 12 mo	Reference
Race/ethnicity	
White, NH	Reference
American Indian or Alaska Native, NH	2.03 (0.77–5.34)
Asian, NH	1.25 (0.59–2.66)
Black or African American, NH	0.42 (0.26–0.67)
Hispanic	0.93 (0.60–1.43)
Multiracial, NH	0.00 (< 0.00–> 999.99)
Native Hawaiian or other Pacific Islander, NH	1.05 (0.16–6.99)
Unknown or not reported	0.96 (0.59–1.57)
Payer type	
Nongovernment	Reference
Government	1.58 (1.12–2.22)
Site	
1	2.92 (1.37–6.20)
2	2.63 (1.25–5.55)
3	4.75 (2.23–10.09)
4	6.15 (2.94–12.85)
5	2.12 (0.98–4.56)
6	3.19 (1.47–6.91)
7	Reference
Primary diagnosis	
Respiratory	Reference
Cancer	3.60 (1.79–7.25)
Cardiovascular disease: acquired	0.86 (0.54–1.36)
Cardiovascular disease: congenital	1.30 (0.71–2.37)
Neurologic	0.57 (0.36–0.91)
Miscellaneous[a]	0.27 (0.14–0.51)
Baseline Functional Status Score	
Good (6, 7)	Reference
Mildly abnormal (8, 9)	2.26 (1.39–3.66)
Moderately abnormal (10–15)	3.37 (2.28–4.99)
Severely abnormal (16–21)	4.55 (2.55–8.11)
Very severely abnormal (> 21)	5.64 (2.72–11.71)
Pediatric Risk of Mortality III	1.56 (1.48–1.65)[b]
Admitted for postoperative care	
No	Reference
Yes	0.33 (0.19–0.56)
Any catastrophic event between 24 hr prior to hospital admission up to PICU admission	
No	Reference
Yes	2.68 (1.72–4.19)
PICU admission status	
Elective	Reference
Emergency	2.26 (1.34–3.81)

OR = odds ratio, NH = non-Hispanic.

[a]Includes diabetic ketoacidosis, musculoskeletal condition, gastrointestinal disorder, hematologic disorder, renal, and miscellaneous.

[b]The OR shows the odds of participating in a limitation or withdrawal of life support discussion for every 3 unit increase in Pediatric Risk of Mortality III score.

Clinical characteristics at the time of death or hospital discharge for children whose families did and did not discuss LWLS with clinicians are shown in **Table 4**. Children whose families discussed LWLS were more likely to die in the hospital ($p < 0.001$) and have worse discharge FSS (< 0.001), POPC ($p < 0.001$) and PCPC ($p < 0.001$) scores than those whose families did not discuss LWLS. Among the 173 children who died after a family discussion about LWLS, 166 (96.0%) died in the PICU, 149 (86.1%) died after LWLS, and 10 (5.8%) after failed cardiopulmonary resuscitation (CPR). Hospital length of stay was shorter for children who died after a family discussion about LWLS with clinicians ($p < 0.01$). Among the 75 children who survived after a family discussion about LWLS, 53 (70.7%) were discharged to home or foster care, 13 (17.3%) to a chronic care or skilled nursing facility, 6 (8.0%) to another acute care hospital, 2 (2.7%) to inpatient rehabilitation, and 1 (1.3%) to inpatient hospice. Twenty-four survivors (32.0%) had severe or very severe functional abnormalities at baseline (FSS > 16), and 40 (53.4%) had severe or very severe functional

abnormalities at discharge. Twenty-eight children (37.3%) who survived after a family discussion about LWLS were discharged with hospice services.

DISCUSSION

Clinician-family discussions about LWLS occurred for a minority of children (2.5%) admitted to the tertiary care PICUs affiliated with the CPCCRN. Little data exist by which to compare the observed frequency of these discussions with that of PICUs outside the CPCCRN. In a recent single-site study investigating the use and content of family conferences among 661 PICU admissions, 34 conferences with a documented discussion about LWLS were identified (9). Of these, 25 discussed "do-not-resuscitate" orders and 9 discussed withdrawal of life

TABLE 4. Clinical Characteristics at Hospital Discharge for Children Whose Families Did and Did Not Discuss Limitation or Withdrawal of Life Support With Clinicians

	Did Not Have Discussions	Had Discussions	
Clinical Characteristics	*n* (%)	*n* (%)	*p*[a]
All patients	*n* = 9,830	*n* = 248	
Death at hospital discharge	102 (1.0)	173 (69.8)	< 0.001
Discharge Pediatric Cerebral Performance Category			< 0.001
Normal	6,492 (66.0)	9 (3.6)	
Mild disability	1,724 (17.5)	10 (4.0)	
Moderate disability	750 (7.6)	6 (2.4)	
Severe disability	669 (6.8)	35 (14.1)	
Coma/vegetative	93 (0.9)	15 (6.0)	
Death	102 (1.0)	173 (69.8)	
Discharge Pediatric Overall Performance Category			< 0.001
Good	3,025 (30.8)	1 (0.4)	
Mild disability	3,903 (39.7)	1 (0.4)	
Moderate disability	1,764 (17.9)	12 (4.8)	
Severe disability	939 (9.6)	46 (18.5)	
Coma/vegetative	97 (1.0)	15 (6.0)	
Death	102 (1.0)	173 (69.8)	
Hospital survivors	*n* = 9,728	*n* = 75	
Hospital discharge Functional Status Score total			< 0.001
Good (6, 7)	6,333 (65.1)	1 (1.3)	
Mildly abnormal (8, 9)	1,446 (14.9)	5 (6.7)	
Moderately abnormal (10–15)	1,359 (14.0)	29 (38.7)	
Severely abnormal (16–21)	444 (4.6)	20 (26.7)	
Very severely abnormal (> 21)	146 (1.5)	20 (26.7)	
Hospital discharge location			< 0.001
Home or foster care	9,074 (93.3)	53 (70.7)	
Chronic care or skilled nursing facility	152 (1.6)	13 (17.3)	
Another acute care hospital	168 (1.7)	6 (8.0)	
Acute inpatient rehabilitation unit	265 (2.7)	2 (2.7)	
Other	69 (0.7)	1 (1.3)	
Discharged with hospice services	18 (0.2)	28 (37.3)	< 0.001

(*Continued*)

TABLE 4. (*Continued*). Clinical Characteristics at Hospital Discharge for Children Whose Families Did and Did Not Discuss Limitation or Withdrawal of Life Support With Clinicians

Clinical Characteristics	Did Not Have Discussions *n* (%)	Had Discussions *n* (%)	*p*[a]
Hospital deaths	*n* = 102	*n* = 173	
Location at time of death (*n* = 275)			< 0.001
PICU	86 (84.3)	166 (96.0)	
Hospital general care	6 (5.9)	6 (3.5)	
Other	10 (9.8)	1 (0.6)	
Mode of death			< 0.001
Failed resuscitation	43 (42.2)	10 (5.8)	
Withdrawal of support	20 (19.6)	121 (69.9)	
Limitation of support	18 (17.6)	28 (16.2)	
Brain death	21 (20.6)	14 (8.1)	
Hospital length of stay, d			< 0.01
Median (first quartile, third quartile)	13.70 (3.70, 51.41)	7.84 (2.22, 19.47)	

[a]*p* value reflects the Cochran-Armitage test for hospital discharge Pediatric Cerebral Performance Category, Pediatric Overall Performance Category, and Functional Status Score total scores, Wilcoxon rank sum test for hospital length of stay, and χ^2 or Fisher exact test for all other variables.

support. Despite their low frequency, clinician-family discussions about LWLS are extremely important clinical interactions because of the gravity of the decisions being made for critically ill children.

Several clinical characteristics present on PICU admission were independently associated with family participation in a discussion about LWLS in our study. These associations can reasonably be expected since the clinical characteristics identified primarily reflect the type and severity of illness. For example, reduced functional status at baseline, recent occurrence of a catastrophic event, emergent PICU admission, and greater physiologic instability may be expected among children at highest risk of poor outcomes and most in need of consideration for comfort rather than curative care. In a recent study comparing PICU family conferences at the bedside versus the conference room, meetings to discuss treatment decisions, redirection of care, or delivery of bad news occurred most often among the sickest children regardless of meeting location (10). These findings are consistent with practice guidelines that acknowledge high-quality communication as an important aspect of end-of-life care and recommend family discussions especially when there is a significant change in treatment course or prognosis (14–16). Our study also found that a primary diagnosis of cancer was independently associated with greater likelihood of LWLS discussions. This may reflect the more terminal nature of some cancer diagnoses, especially when complicated by serious illness requiring PICU admission.

Families of children with government health insurance were more likely to discuss LWLS with clinicians than those with nongovernment insurance in our study. Prior research has shown that children with government insurance have higher severity of illness on PICU admission compared with children with other payment types (26), which could prompt LWLS discussions. Another possibility for this finding is the availability of public funding for children with chronic complex conditions. For example, Children's Special Health Care Services is a federal program under Title V of the Social Security Act available to children with chronic complex conditions (27). Prior research has shown that PICU family meetings occur most often with parents whose children have chronic complex conditions (9).

Black race was independently associated with lower likelihood of a clinician-family discussion about LWLS. Studies in neonatal, pediatric, and adult ICUs have shown a preference among African Americans for full support at the end of life (28–31). Distrust of the healthcare system and personal experiences with access to care have been suggested as potential explanations for these observations (32). Postoperative status was also independently associated with lower likelihood of LWLS discussions. Children admitted to PICUs after scheduled surgery may be less in need of LWLS discussions because recovery is expected. However, research among adult patients suggests a surgical reluctance toward LWLS grounded in surgeons' strong sense of responsibility for surgical outcomes (33, 34). Clinical site was independently associated with likelihood of LWLS discussions. Prior CPCCRN research has shown that morality rate and mode of death did not vary significantly across sites when assessed during the same time period as the current study (35). The association between clinical site and LWLS discussions observed in this study may reflect variation

in institutional practice, documentation of discussions, or other factors.

Most children whose families discussed LWLS during their PICU stay died during their hospitalization. Of those who died, most died in the PICU after a decision to limit or withdraw life support had been made. However, a minority of children whose families discussed LWLS died after failed CPR, which may indicate conflict between clinicians and families. Details regarding conflicts between clinicians and families during LWLS discussions are not available in the database from which this secondary analysis was performed. Our data also show that some children whose families did not discuss LWLS during their PICU stay died after LWLS was performed. Families of these children possibly had LWLS discussions with clinicians before or after their child's PICU stay; data on LWLS discussions before or after the PICU stay were not collected in this study. Another possible explanation is that some LWLS discussions occurring during the PICU stay were missed despite data collection via medical record review, direct observation, and discussion with bedside clinicians. For example, a diverse and large number of intensivists, bedside nurses, advanced care practitioners, fellows, residents, palliative care physicians, and subspecialists might encounter a family in formal or informal clinical settings and initiate LWLS discussions that were missed in our data collection. Also, the use of advanced directives or durable power of attorney was not collected. Notably, about one third of children whose families discussed LWLS during their PICU stay survived their hospitalization and were discharged to various locations including home or foster care, chronic or skilled nursing facilities, other acute care hospitals, inpatient rehabilitation, or inpatient hospice. Of these, most had substantial disabilities based on discharge FSS, PCPC, and POPC scores. One third of children who survived after LWLS discussions were discharged with hospice services.

Strengths of this study include the random selection of children from a national network of tertiary care PICUs with geographic variability and the prospective collection of data. Limitations include identification of only those clinician-family discussions about LWLS that occurred during the child's PICU stay and the possibility that some of these LWLS discussions were missed during data collection. Another limitation is the lack of detail available on the LWLS discussions such as initiator (e.g., clinicians and parents), participants (e.g., subspecialists, nurses, and chaplains), location (e.g., bedside and conference room), specific content, and number of discussions per child. Also, the proportion of children (9.1%) whose race/ethnicity was unknown or not reported is relatively large, and there is potential for misclassification of race/ethnicity when not collected directly from children or families by self-report. Other factors such as family and clinician characteristics are also likely to influence family participation in LWLS discussions. For example, physician-related variability in end-of-life decision making within and between ICUs has been well documented (36). However, only the sociodemographic and clinical characteristics of the children were explored in this study. Our findings do neither elucidate whether some of the LWLS discussions identified in this study were premature or inappropriate nor provide insight regarding the effects of premature or inappropriate discussions on families. These are important areas for future research.

CONCLUSIONS

Our findings suggest that clinician-family discussions about LWLS occur for a minority of children cared for in PICUs. Clinical factors reflecting type and severity of illness, sociodemographics, and institutional practices may influence whether LWLS is discussed with families of PICU patients. Although most children whose families discuss LWLS die during their PICU stay, many survive with substantial disabilities. Increased availability of hospice services may be warranted for these children.

ACKNOWLEDGMENT

We thank Jean Reardon, MA, BSN, RN, Children's National Medical Center; Aimee La Bell, MS, RN, Phoenix Children's Hospital; Margaret Villa, RN, Children's Hospital Los Angeles and Mattel Children's Hospital; Jeni Kwok, JD, Children's Hospital Los Angeles; Ann Pawluszka, BSN, RN, Children's Hospital of Michigan; Monica S. Weber, RN, BSN, CCRP, University of Michigan; Alan C. Abraham, BA, CCRC, University of Pittsburgh Medical Center; Mary Ann DiLiberto, BS, RN, CCRC, Children's Hospital of Philadelphia; Teresa Liu, MPH, CCRP, University of Utah; Jeri Burr, MS, RN-BC, CCRN, University of Utah; and Susan L. Bratton, MD, University of Utah.

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