Alterations in End-of-Life Support in the Pediatric Intensive Care Unit

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WHAT'S KNOWN ON THIS SUBJECT: Studies from the 1990s demonstrated limitation of end-of-life support in 30% to 58% of US PICU deaths. Little has been published from the United States since that time. More-recent publications from Australia showed limitation in 74% to 84% of deaths.

WHAT THIS STUDY ADDS: The authors address a gap in the literature by describing recent end-of-life support practices in 30 PICUs across the United States.

abstract

OBJECTIVE: Our purpose was to examine alterations in end-of-life support in a multiinstitutional sample of PICUs.

METHODS: This was a retrospective, descriptive study. Variables collected included end-of-life support category, race, length of stay, operative status, reason for admission, and Pediatric Index of Mortality 2 score, as well as the number of ICU beds and the presence of trainees.

RESULTS: There were 1745 deaths at 35 institutions between January 1, 2004, and September 30, 2005. Of those, 1263 had complete data and were analyzed. The end-of-life support category distribution was as follows: brain death, 296 (23%); do not resuscitate, 205 (16%); limitation of support, 36 (3%); withdrawal of support, 579 (46%); no limitation, 124 (10%); no advance directives, 23 (2%). For further analyses, end-of-life support categories were grouped as limitation (ie, do not resuscitate, limitation of support, or withdrawal of support) versus no limitation (ie, no limitation or no advance directive). Brain death was not included in further analyses. The majority of deaths were in the limitation group ($n = 820$ [85%]), and 12 (40%) of 30 institutions had 100% of deaths in this group. There were significant differences between institutions ($P < .001$). Decisions for limitation were seen less frequently in the black race (112 [76%] of 147 deaths; $P = .037$) and in institutions with no trainees (56 [69%] of 81 deaths; $P < .001$).

CONCLUSIONS: Decisions to limit support are common. Black race and an absence of trainees are associated with decreased frequency of limitation decisions. *Pediatrics* 2010;126:e859–e864

The death of a child is an important but relatively uncommon occurrence. In 2006, there were 53 046 pediatric deaths, representing ~2% of deaths in the United States.[1] Like many other pediatric health-related issues, the relative infrequency of childhood death makes it difficult to study. The Institute of Medicine observed that there is inadequate scientific knowledge related to pediatric end-of-life care and that families often do not receive sufficient support when this devastating event occurs.[2]

Although knowledge regarding pediatric death is limited, it is known that the majority of pediatric deaths occur in inpatient settings, often in ICUs.[2] Advances in medical technology have allowed us to support failing organ systems, which has resulted in improved survival rates for previously fatal conditions. These technologic advances do not guarantee a recovery of health to a state consistent with any given family's desired quality of life for their child. Families and providers may view the technology as simply maintaining an undesired state or even postponing death, rather than sustaining life. In such circumstances, families may elect to limit or to withdraw support.

In the early 1990s, several single-center studies demonstrated that limitations of support occurred for 30% to 58% of deaths.[3–6] One multicenter study of PICU admissions in 1989–1992 demonstrated that some degree of limitation of support preceded 38% of deaths.[7] Since those studies from the 1990s, little has been published regarding the prevalence of limitation of support in US PICUs. One single-center study published in 2000, with data from 1996, reported limitation of support for 52% of deaths.[8]

More-recent studies were performed at PICUs in other countries, with variable results. Multiinstitutional studies from Brazil (3 institutions) and Argentina (16 institutions) showed that most pediatric patients in those countries received full support and underwent cardiopulmonary resuscitation before death.[9,10] Conversely, studies from France (9 institutions), Malaysia (1 institution), Netherlands (1 institution), and Canada (1 institution) demonstrated that limitation of support occurred for just more than one-half of deaths.[11–14] The most-recent studies came from Australia in 2008, with data from 2006 and 2007. Those 2 single-institution studies showed limitation of support for 74% and 84% of pediatric deaths.[15,16]

The scarcity of literature from the United States in the previous decade and the overall paucity of pediatric multiinstitutional studies led us to examine the patterns of pediatric deaths and end-of-life care in PICU settings in a multiinstitutional cohort from across the country. Are we still limiting support in just more than one-third of pediatric deaths, as shown in 16 US PICUs in 1994, or are we closer to the numbers reported recently from Australia?[7,15,16] We aimed specifically to understand how frequently limitations of support occurred at the end of life in PICU settings in the United States and sought to identify variations in end-of-life practices related to specific PICU and patient variables.

METHODS

This was a retrospective, observational study to describe patterns of limitations of support in a multiinstitutional cohort of PICUs. Data were obtained from a VPS, LLC (Milwaukee, WI) database, a multiinstitutional, pediatric, critical care, clinical database. All deaths during the study period of January 1, 2004, to September 30, 2005, were included. Variables collected included end-of-life support category, age, race, gender, length of stay, severity of illness, admission type, operative status, reason for admission, primary diagnosis, and trauma status. Institution-specific data, including the number of PICU beds and the presence of trainees, also were collected. No protected patient health information was used in the study, and the study was determined by the human research review board to be exempt from requirements for review.[4]

For each patient death, centers collected data related to end-of-life support according to the following instructions: "If applicable, select from the drop-down list the situation that best describes the situation at time of discharge." The drop-down menu included the following 6 options: brain death, do not resuscitate, limited care, withdrawal of care, no limitation of care, and no advance directives obtained. The field allowed only 1 response to be selected. For purposes of analysis, we separated out deaths identified as brain death. In the United States, a patient who is declared brain dead is already legally dead; therefore, there are no additional opportunities for decision-making regarding end-of-life support. All deaths not identified as brain death were classified into 1 of 2 groups, that is, limitation or no limitation. The limitation group included deaths for which the end-of-life support category identified was do not resuscitate, limited care, or withdrawal of care. The no-limitation group included deaths for which the end-of-life support category identified was no limitation of care or no advance directives obtained.

Analysis was performed with SPSS 15.0 (SPSS Inc, Chicago, IL). Continuous variables were expressed as means and SDs (if data were normally distributed) or medians and interquartile ranges (if data were not normally distributed). Categorical variables were summarized as proportions. Differences between groups were evaluated

by using Student's *t* tests (comparing normally distributed variables) or Wilcoxon or Mann-Whitney *U* tests (comparing variables that were not normally distributed). Fisher's exact tests or χ^2 tests were used to compare proportions.

RESULTS

We collected data on 1745 deaths among 55 987 admissions at 35 PICUs. Data from 5 PICUs (219 deaths) were excluded because of PICU-specific decisions not to capture data included in this study. Of the remaining 1526 deaths, 1263 deaths from 30 PICUs had complete variables for all fields and thus were included in analyses.

The cohort reflected a range of PICU sizes and presence of trainees (Table 1). The numbers of deaths per center during the study period ranged from 2 to 150 deaths per center, with a median of 27.5 deaths per center. Some centers participated in data collection for only a portion of the study period.

The distribution of end-of-life support categories for all deaths and our subsequent classification into limitation and no-limitation groups are presented in Table 2. Comparisons between the limitation and no-limitation groups revealed significant differences in patient race and the presence of trainees (Table 3). The difference in patient length of stay approached statistical significance. In addition to the data presented in Table 3, there were

TABLE 2 Distribution of End-of-Life Support Categories

	n (%)
Total	1526
Missing data	263
Complete data	1263 (100)
Brain death	296 (23)
Do not resuscitate	205 (16)
Limited care	36 (3)
Withdrawal of care	579 (46)
No limitation of care	124 (10)
No advance directive	23 (2)
Deaths with opportunities for decision-making	967
Limitation group	820[a]
No-limitation group	147[b]

[a] Represents 65% of all deaths with data and 85% of deaths with opportunities for decision-making.
[b] Represents 12% of all deaths with data and 15% of deaths with opportunities for decision-making.

no significant differences in established database categories of trauma status, completion of autopsy, organ donation, or primary diagnosis. There were significant differences between institutions in the proportions of deaths in the limitation group (Fig 1). Proportions of deaths in the limitation group ranged from 50% to 100%, with 12 of the 30 institutions limiting support for 100% of deaths not declared brain death.

DISCUSSION

This study sought to examine the patterns of pediatric death and end-of-life care in PICU settings, by using a multi-institutional cohort. We aimed specifically to understand how frequently limitations of support occurred at the end of life in PICU settings and to identify variations in end-of-life practices

TABLE 1 Characteristics of Studied PICUs

	No.		
	Institutions With <20 Beds	Institutions With ≥20 Beds	Total
No trainees	2	2	4
Residents present	6	5	11
Residents and fellows present	4	11	15
Total	12	18	

TABLE 3 Comparison of Limitation and No-Limitation Groups

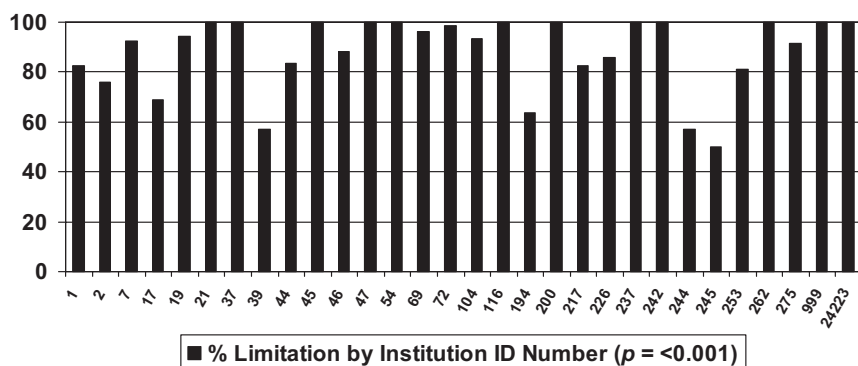|	Total	Limitation	No Limitation	*P*
N (%)	967 (100)	820 (85)	147 (15)	
Age, mean ± SD, mo		68.1 ± 85.9	67.5 ± 82.8	NS
Male, *n* (%)	547 (56.6)	472 (57.6)	75 (51.0)	NS
Race, *n* (%)				.037
White	600 (65.9)	511 (66.4)	89 (63.1)	
Hispanic	95 (10.4)	81 (10.5)	14 (9.9)	
Black	147 (16.2)	112 (14.6)	35 (24.8)	
Other	68 (7.5)	65 (8.4)	3 (2.1)	
Missing data	57			
Pediatric Index of Mortality 2 score, mean ± SD		0.23 ± 0.30	0.24 ± 0.30	NS
Admission reason, *n* (%)				NS
Cardiovascular/shock	384 (40.3)	316 (38.8)	68 (48.9)	
Respiratory failure	321 (33.6)	283 (34.7)	38 (27.3)	
Neurologic	114 (11.9)	103 (12.6)	11 (7.9)	
Metabolic	23 (2.4)	17 (2.1)	6 (4.3)	
Hematologic/coagulation	19 (2.0)	16 (2.0)	3 (2.2)	
Procedure	4 (0.4)	3 (0.4)	1 (0.7)	
Other	89 (9.3)	77 (9.4)	12 (8.6)	
Missing data	13			
Scheduled admission, *n* (%)	160 (16.5)	133 (16.2)	27 (18.4)	NS
Operative status, *n* (%)				NS
Nonoperative	676 (69.9)	584 (71.2)	92 (62.6)	
Preoperative	81 (8.4)	68 (8.3)	13 (8.8)	
Postoperative	210 (21.7)	168 (20.5)	42 (28.6)	
Length of stay, mean ± SD, d		14.9 ± 25.5	10.7 ± 18.9	.055
PICU size, *n* (%)				NS
<20 beds	166 (17.2)	140 (17.1)	26 (17.7)	
≥20 beds	801 (82.8)	680 (82.9)	121 (82.3)	
Presence of trainees, *n* (%)				<.001
No trainees	81 (8.4)	56 (6.8)	25 (17.0)	
Residents (with or without fellows)	886 (91.6)	764 (93.2)	122 (83.0)	
No fellows	406 (42.0)	349 (42.6)	57 (38.8)	
Fellows	561 (58.0)	471 (57.4)	90 (61.2)	

NS indicates not significant.

FIGURE 1
Proportions of deaths in the limitation group according to institution.

related to specific PICU and patient variables.

This study of 30 PICUs is the largest study of patterns of death in PICUs to date, and it demonstrates that the practice of limiting support at the end of life (including altered code status, limitation of support, and withdrawal of support) is ubiquitous, with limitations occurring at all hospitals in the study. Occurrences of limitation of support not only are widespread but also are frequent, with 40% of the institutions in this study limiting support in 100% of deaths involving patients who were not declared brain dead. All institutions limited support ≥50% of the time for patients who were not declared brain dead. Our findings demonstrate that the overall rates of limitation of support are increased, compared with the findings of studies that examined practices in the United States 2 decades ago.[3–7] This is consistent with the findings of articles that examined trends in limitation of support in 2 NICUs over 10-year and 16-year periods, with the later rates of limitation of support being 64% and 80%, respectively.[17,18]

Despite the widespread prevalence of limitation of support, there were significant differences in rates of limitation between institutions. This is consistent with reports from adult institutions.[19–21] It is also consistent with a recent study that examined neonatal deaths in a cross-cultural cohort of 4 institutions.[22] This neonatal study demonstrated high overall rates of limitation of support (83%–98%) and showed significant differences even among centers in the midwestern United States. There are many possible reasons for the variability among centers. One recent, large, adult study showed that independent predictors of decisions to forgo life-sustaining treatment included institutional variables such as the presence of an emergency department, ICU size, nurse staffing ratios, and physician coverage models.[19] The differences seen in our study may reflect the individual and personal nature of end-of-life decisions and the influence of locally predominant cultures and religions.

Our study did show that centers with no trainees (residents or fellows) had lower rates of limitation of support. There was no difference according to the presence or absence of fellows if a program had residents. The generalizability of these results is unclear, because we had only 4 institutions without trainees in our cohort, and most of the deaths in that group (63 of 81 deaths) were from a single institution. Although this may reflect true differences between programs with or without trainees, future work is needed to confirm this observation.

Race was found to be associated with significant differences in rates of limitation of support, with limitation being less frequent in the black population. Racial differences in end-of-life decision-making were reported previously in the adult literature.[23–26] The adult studies showed that a consistent theme among black families is the preference for life support. Several small studies of end-of-life decisions in NICUs demonstrated similar findings.[27–29] Our study and the neonatal studies are important because they demonstrate that black adults not only prefer life support for themselves but also make similar decisions for their critically ill neonates and children. Previous studies speculated on the reasons for this preference, including distrust of the health care system and previous personal experiences with access to care. Our study was not designed to examine the reasons behind individual decisions.

Our study found a trend toward longer lengths of stay in the limitation group. Although our results did not reach statistical significance, this finding was reported in other pediatric studies.[3,9,11,13,14]

We did not find a difference in the severity of illness, as measured with the Pediatric Index of Mortality 2, between the no-limitation and limitation groups. One possible explanation is that the Pediatric Index of Mortality 2 is measured within the first hour after arrival in the PICU and does not reflect the complex circumstances that may develop subsequently and affect end-of-life decision-making. Another possible explanation is the likelihood that the patients who died all had a relatively high severity of illness and the gradations between them were too small to be significant.

There are several possible limitations to our study. One limitation is the potential for misclassification of

deaths by the institutions entering the data. This potential for misclassification of data exists in any database study; however, it is mitigated somewhat in this study through the use of standard definitions. The VPS database has been shown to have interrater reliability of >95% for data collection and entry, on the basis of ongoing quarterly evaluations.

A second limitation is that the database design allowed only 1 choice of support category per death, which means that, for patients who were classified as brain dead, no information was available regarding limitation decisions that might have occurred before the declaration of brain death. For this reason, we focused our analysis on limitations versus no limitations

and excluded patients who were declared brain dead.

A third limitation is related to the terminology already in use for the database, particularly "limited care," "withdrawal of care," and "advance directives." We would like to think that care itself is never limited or withdrawn but the goals of care shift such that nonbeneficial treatment is limited or withdrawn. In addition, it would be more appropriate to use terms such as "advance care planning" or "anticipatory discussions" instead of "advance directives," which typically are created by competent adults to guide their own future care and are not used for pediatric patients. Despite our preference for more-appropriate terminology, we were limited by that already in use for the database. A final

limitation is the inability of the study to explore the reasons behind the differences seen, rather than just establishing whether differences or patterns existed. Future work may explore these differences in more detail.

CONCLUSIONS

We found that limitation of support at the end of life for children in PICU settings is more common in the United States now than it was 10 to 15 years ago, occurring for the majority of deaths and in every institution in our cohort. There was significant variability among institutions. Black race and an absence of trainees were associated with decreased frequency of limitation of support. Further work may explore these differences in more detail.

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