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Circumstances Surrounding End of Life in a Pediatric Intensive Care Unit

Daniel Garros, MD*; Rhonda J. Rosychuk, PhD‡; and Peter N. Cox, MD*

ABSTRACT. *Objective.* Approximately 60% of deaths in pediatric intensive care units follow limitation or withdrawal of life-sustaining treatment (LST). We aimed to describe the circumstances surrounding decision making and end-of-life care in this setting.

Methods. We conducted a prospective, descriptive study based on a survey with the intensivist after every consecutive death during an 8-month period in a single multidisciplinary pediatric intensive care unit. Summary statistics are presented as percentage, mean \pm standard deviation, or median and range; data are compared using the Mantel-Haenszel test and shown as survival curves.

Results. Of the 99 observed deaths, 27 involved failed cardiopulmonary resuscitation; of the remaining 72, 39 followed withdrawal/limitation (W/LT) of LST, 20 were do not resuscitate (DNR), and 13 were brain deaths (BDs). Families initiated discussions about forgoing LST in 24% (17 of 72) of cases. Consensus between caregivers and staff about forgoing LST as the best approach was reached after the first meeting with 51% (35 of 68) of families; 46% (31 of 68) required ≥ 2 meetings (4 not reported). In the DNR group, the median time to death after consensus was 24 hours and for W/LT was 3 hours. LST was later withdrawn in 11 of 20 DNR cases. The family was present in 76% (45 of 59) of cases when LST was forgone. The dying patient was held by the family in 78% (35 of 45) of these occasions.

Conclusions. More than 1 formal meeting was required to reach consensus with families about forgoing LST in almost half of the patients. Families often held their child at the time of death. The majority of children died quickly after the end-of-life decision was made. *Pediatrics* 2003;112:e371–e379. URL: <http://www.pediatrics.org/cgi/content/full/112/5/e371>; *withdrawal of therapy, death, futility, pediatric intensive care, ethics, attitude of health personnel, critical care, decision making, drug utilization, passive euthanasia, human, intensive care units, life support care, palliative care.*

ABREVIATIONS. ICU, intensive care unit; LST, life-sustaining treatment; PICU, pediatric intensive care unit; HSC, Hospital for Sick Children; BD, brain death; DNR, do not resuscitate; RES,

resuscitation; ALS, advanced life support; W/LT, withdrawal or limitation of therapy; CPR, cardiopulmonary resuscitation; LOS, length of stay; ECLS, extracorporeal life support; NMB, neuromuscular blocking agent.

Up to 90% of deaths in adult intensive care units (ICUs) in North America follow an order to forgo life-sustaining treatment (LST).^{1,2} In pediatric ICUs (PICUs), retrospective studies done during the past decade indicate that 40% to 60% of all deaths follow such a decision.^{3–7} However, few of these reports describe how these decisions were reached.^{7–10} A more recent study analyzed 53 deaths in 3 PICUs in the United States in which LST was forgone. The author's focus was on the medications given at the end of life and the physicians' and nurses' levels of satisfaction with the care provided.¹¹ The revelation about the presence of paralyzing agents in some patients at the time of withdrawal of LST and that 2% of the involved professionals believed that hastening death is an acceptable goal in itself generated great controversy.^{12–14} Consequently, more information about pediatric intensivists' actual practices regarding forgoing LST in children^{8,10,15,16} is warranted. Some details about these events, such as timing of decision making, terminal sedation, barriers to achieve consensus with families, and their participation in the process, remain topics that need additional exploration.^{17,18}

The purpose of this study was not only to determine the modes of death in a single large multidisciplinary PICU in Canada but also to describe the decision-making process and the end-of-life care. We also examined the level of difficulty to reach consensus with families or surrogates about forgoing LST, a facet not well described in this population. This is a descriptive study based on a self-administered questionnaire completed by the most responsible intensivist after every consecutive death in our PICU.

METHODS

This study was conducted in the PICU of the Hospital for Sick Children (HSC), a multidisciplinary unit with 36 beds, 5 full-time staff physicians, 8 clinical fellows, and 1 or 2 rotating pediatric residents. There are approximately 2000 admissions per year, 35% to 45% of which are cardiac surgery patients. The unit is the largest in the country, serving an urban population of approximately 5 million in the south central region of Ontario, Canada.

Questionnaire

We conducted a prospective analysis of all deaths that occurred in the unit over 8 months (1995–1996). This time interval was selected for convenience and practicality. For every child who died, the physician involved with the patient completed a written questionnaire within 24 hours of the death. The survey was given

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to the intensivist as part of the "death package" (death certificate, checklist for nurses and physicians, autopsy consent form, etc), and it was self-administered. On a few occasions, the principal investigator consulted with the responsible physician for clarification purposes (see below). A pilot study was performed for 6 months in the previous year, allowing the PICU staff to become familiar with the study terminology and to modify and refine the survey format.

The questionnaire contained several types of questions, such as precoded simple, multiple-choice, open-ended, ranking-order, and branching. It documented the patient's characteristics, admission diagnosis, number of formal meetings with families (as a surrogate of the level of difficulty to reach consensus), mode of death, the time from decision to forgo LST to death, family presence at the time of death, and other items. Every patient was classified at the time of death by the patient's intensivist according to the following parameters:

1. Brain death (BD): when criteria for brain death were met¹⁹⁻²¹
2. Do not resuscitate (DNR): when a DNR order was clearly previously documented^{22,23}
3. Failed resuscitation (RES): when either advance life support (ALS) failed to restore circulation or increasing doses of epinephrine infusion failed to maintain cardiac activity
4. Withdrawal or limitation of therapy (W/LT): when medical staff and family agreed that the present level of LST would be limited and/or the child would be actively removed from inotropes and/or mechanical ventilation²⁴.

The physicians were asked to give reasons for forgoing LST, as a result of their interactions with the families. The following options were available for response, according to the model used by Mink et al⁴ and originally described by Tomlinson and Brody²⁵: 1) additional medical therapy of no benefit (eg, cancer untreatable); 2) present quality of life is unsatisfactory (eg, neurovegetative state); 3) if a new cardiac arrest occurs, then additional life quality would be unsatisfactory; and 4) other (open-ended question).

To improve the accuracy of the survey, several steps were taken. The sections related to demographics, the child's diagnosis, and the levels of support were confirmed by reviewing the PICU database, the death summary files, and the mortality review committee minutes. All patients who had "terminal weaning and/or terminal extubation" had their hospital charts audited to validate the information about the use of paralyzing agents. The principal investigator (D.G.) reassessed the initial classification of the type of death and demographic information with the responsible physician in 13 of the 99 cases (5 WT/L, 5 DNR, and 3 RES) to ensure the accuracy of the responses and obtain missing data. For example, some patients underwent cardiopulmonary resuscitation (CPR) a few hours before having LST withdrawn or withheld, hence the need for additional clarification.

In this PICU, decisions regarding limiting or withdrawing LST are multidisciplinary and family centered. A hospital bioethical committee is available for consultation if required. The family members are encouraged to be at the bedside and to hold their child immediately before or during the process of discontinuation of LST, should they so wish.

As per previous agreement among all PICU staff and the hospital research board, written informed consent was not obtained for this research. Accordingly, all physicians participated in the study on a voluntary basis after an ample consultation process. Therefore, by reading the introductory letter attached to the study questionnaire and returning it completed to the investigators, the physicians agreed to participate. Because the study did not in-

volve any direct patient intervention or data collection that could in the future potentially identify a particular case, seeking informed consent from families or surrogates was considered unwarranted.

Statistical Analysis

Summary statistics are presented as percentage, mean \pm standard deviation, or median and range where appropriate. The Kruskal-Wallis rank sum tests were used to test the equality of the highly skewed age distributions. The time to death and decision data are represented as survival curves and compared with Mantel-Haenszel tests.²⁶ Categorical data were analyzed using Fisher exact test, and multiple comparisons were corrected with the Bonferroni method. $P = .05$ was considered to be significant for the whole-group analyses.

RESULTS

During the study period (8 months), there were 99 deaths (7.3%) in the PICU out of a total of 1359 discharges from the unit. PICU deaths corresponded to 52.3% (99 of 189) of the hospital deaths. The modes of death were W/LT in 39.4% (39 of 99), RES in 27.3% (27 of 99), DNR in 20.2% (20 of 99), and BD in 13.1% (13 of 99; Table 1).

Fifty-six percent (56 of 99) were male. The median age of the study group was 0.78 years, or 9.3 months (range: 1 day-17.2 years). Summary values for the patient's ages are shown in Table 1. The age distributions were different among the 4 groups (Kruskal-Wallis = 19.05, $df = 3$; $P < .001$). RES patients were younger than both BD ($P < .001$) and DNR patients ($P = .006$). In addition, the W/LT patients were younger than the BD ($P = .002$) patients.

The mean length of stay (LOS) in the PICU for all patients admitted during the study period was 3.8 days (range: 1 day-6 months). In contrast, the study population stayed for an average of 4.94 days (range: 1-38 days) in the PICU. Summary measures are given in Table 1. The LOS of the DNR and W/LT groups was longer than the RES and BD (Mantel-Haenszel = 24.8, $df = 3$; $P < .001$).

Socioeconomic Data

The spectrum of family backgrounds and reported religion reflects the region's population composition at the time.²⁷ A total of 67.7% (67 of 99) of the patients were Anglo-Saxon, and 10.1% (10 of 99) were of Indo-Pakistani descent. Four patients were of Middle Eastern, 4 of Canadian Aboriginal, 4 of Italian, 3 of Chinese, 3 of Caribbean, and 1 of Israeli descent. The ethnic origin was not described in 3 cases. Unemployed caregivers composed 20.2% (20 of 99), versus a regional unemployment average of 9% to 10% during the same period.²⁸

Religious background reflected the population

TABLE 1. Modes of Death (*n*), Age, and LOS

	DNR	BD	W/LT	RES
Age (y)				
Mean (SD)	4.52 (6.13)	6.31 (4.54)	2.56 (3.92)	1.29 (3.29)
Median (range)	1.42 (0.00-17.23)	6.61 (0.40-13.84)	0.84 (0.00-16.05)	0.08 (0.00-14.54)
LOS (d)				
Mean (SD)	8.11 (7.86)	1.99 (2.17)	6.20 (7.09)	2.20 (2.66)
Median (range)	5.53 (0.25-28.17)	1.27 (0.53-0.80)	3.21 (0.26-37.14)	0.93 (0.01-10.61)
Total (<i>n</i>)	20	13	39	27

SD indicates standard deviation.

base: 31.3% (31 of 99) of parents or legal guardians were Roman Catholic, 25.3% (25 of 99) were Protestant, 5 were Hindu, 4 were Sikh, 3 were Moslem, 2 were Jewish, 1 was Buddhist, and 1 was Jehovah's Witness. In 26.3% (26 of 99) of the cases, the religion was not voluntarily disclosed (as this is not required by hospital policy) or the parents reported other or no religion.

Admission Diagnosis and Cause of Death

Admission diagnoses were categorized as medical, cardiac surgery, trauma, postsolid organ transplantation (liver, kidney, and heart), and other surgery as shown in Table 2. Trauma patients were more often BD cases, and medical and cardiac surgery patients were predominantly W/LT and RES cases, respectively (Fisher exact test, $P = .001$).

The primary PICU admitting diagnoses of the study population were heart disease (including both medical and postsurgery cases) in 46.5% (46 of 99), malignancies in 14.1% (14 of 99), acute respiratory failure associated with infection in 8, postsolid organ transplantation in 7, trauma in 6, persistent pulmonary hypertension of the newborn in 6, congenital diaphragmatic hernia in 5, and other conditions in 7. Table 3 portrays the final conditions reported by the physicians as immediately preceding death.

Decision Making and End-of-Life Care for the DNR, W/LT, and BD Groups ($N = 72$)

In all 72 cases classified as DNR, W/LT, and BD, formal meetings with the families or surrogates were held. The family spontaneously raised the issue of limiting or withdrawing LST in 23.6% (17 of 72). The BD group was included in this analysis for 2 reasons: 1) because we found some resistance to discontinuing therapy in 5 of the 13 cases; and 2) because of the sudden nature of these events, we sought to evaluate the interaction between staff and families.

After initial informal conversations with the family at the bedside, a more formal meeting was usually called to discuss goals and choices regarding additional therapy. The intensivists would then explain the options available and try to reach common goals for additional management. The attending physician was present at all of the gatherings. Nurses attended in 75% (54 of 72), fellows in 62.3% (45 of 72), residents in 52.8% (38 of 72), social workers in 29.2% (21 of 72), chaplains in 9.7% (7 of 72), and an interpreter was required for 4 cases. Hospital ethics representatives were involved on 1 occasion. Judicial review was not obtained in any case.

TABLE 2. Admission Category

Class	Medical ($n = 48$)	Surgical* ($n = 10$)	PO-Card ($n = 28$)	Trauma ($n = 6$)	Transplant† ($n = 7$)
BD	6	2	1	4	0
DNR	13	1	3	1	2
RES	7	3	16	0	1
W/LT	22	4	8	1	4

PO Card indicates postsurgical repair of congenital heart disease.

* Other surgical.

† Includes only solid organ transplant (liver, kidney, and heart).

TABLE 3. Final Diagnosis at the Time of Death

	DNR	RES	W/LT	BD
Respiratory failure	4	2	9	-
Cardiac surgery complications	2	16	8	1
Sepsis*	3	3	8	1
Transplant complications†	2	1	3	-
BM transplant complications	1	-	3	-
Solid tumor, terminal stage	2	-	-	1
Neurodegenerative disease	3	-	-	-
Severe CNS insult	1	-	3	-
MODS	1	2	2	-
Trauma (burn, MVA)	-	-	1	5
Cardiogenic shock (not-po)	1	-	2	-
Brain A-V malformation	-	-	-	1
Asphyxia	-	-	-	2
Other	-	3	-	2
Total	20	27	39	13

BM indicates bone marrow; CNS, central nervous system; MODS, multiorgan dysfunction syndrome; A-V, arterial-venous; MVA, motor vehicle accident.

* Sepsis and MODS were present as contributing factors in many terminal events. MODS was listed in 15 cases; sepsis/septic shock in 19 cases.

† Solid organ (liver, heart and kidney).

A consensus about forgoing LST was achieved in the first formal "sit-down" meeting with families or surrogates in 51.4% (35 of 68). In 17.6% (35 of 68), 2 formal meetings were required, and in 28% (19 of 68), >2 meetings were held for sharing information. On 1 occasion, no complete agreement was reached. The parents of an adolescent who had a diagnosis of brain death after trauma had trouble understanding the BD concept. Resuscitation was not provided at the time of a cardiac arrest, and the family subsequently accepted the decision. In another particularly challenging case, the parents of an infant with severe pertussis declined the option of extracorporeal life support (ECLS) on the basis of their religious beliefs, a decision that was respected. In 4 cases, no details were available and the respondents could not recall the information.

When exploring the factors involved in the degree of difficulty reaching consensus, we empirically subdivided these families into 1 meeting (35 of 68), ≥ 2 meetings (33 of 68), or no consensus. Four cases were not included in this analysis because of lack of complete information. No association was found among type of family (eg, parents alone, divorcees, single parent, grandparents), employment status, racial background, admission category (medical, postgeneral surgery, postcardiac surgery, transplant, or trauma) and the level of difficulty reaching agreement. Religious background was the only factor that demonstrated some association with the level of difficulty to reach consensus. Among the 15 Protestant families, 73.3% (11 of 15) reached consensus after the first gathering and 3 required >1 meeting; 1 case was unknown. Among the 5 Hindu families, several meetings were held to reach consensus in 4 cases, and with 1 family, 2 meetings were convened (Fisher exact test, $P = .028$). In 2 BD cases (meningitis, non-accidental injury), 2 meetings were held and 3 cases (trauma, blocked shunt, and septic emboli postheart surgery) required several meetings.

Use of Analgesics/Sedatives (n = 59)

The 13 BD patients were excluded when assessing analgesia and sedation usage. In 96.3% of the 54 patients in which this information was recorded (5 had no answer), some form of sedation or analgesia to alleviate discomfort and/or pain was in use at the time of death. Two patients did not receive medications because they were totally unresponsive, although they were not BD. Reflecting the current PICU practice, the most frequently used agent was morphine as a continuous infusion in 94.4% (51 of 54) of patients. The infusion rate was increased around the time of death in 20.4% (11 of 54). In 3 children (W/LT group), an extra dose of narcotic was given, and in 4 situations, other sedatives were used in isolation or combination with morphine.

In 20.4% (11 of 54) of the patients, the physician reported that a neuromuscular blocking agent (NMB) administration order was still in effect at the time of death; however, no doses were given after the decision to forgo LST was made. The timing of the last dose of NMB actually given was not requested. The principal investigator audited these patients' charts and death summaries to confirm these data. It is the practice at the HSC PICU not to use continuous infusion of NMB, so at all times, doses were intermittently given. In 8 of these 11 cases, ventilation was not discontinued; 3 children had DNR orders that were maintained, 1 underwent limitation of LST, 2 had only inotropic support removal, and 2 were cardiac patients in refractory shock removed from ECLS. Only 3 of these 11 ventilated patients underwent "terminal extubation." Two of them had diaphragmatic hernia exhibiting refractory hypoxemia despite maximum therapy before extubation. The decision to withdraw was made at the bedside with 1 family 5 minutes before their child died, and in the other case, it was 3 hours before death. The final case was an infant in refractory cardiogenic shock after cardiac surgery who had inotropes discontinued along with terminal extubation. This occurred when he was already bradycardic.

Physicians' Reasoning for Limiting or Withdrawing Therapy

On this question, physicians were allowed to choose >1 option; hence, 73 answers were obtained for the 59 cases of W/LT and DNR (BD and RES excluded). The most frequent response (68.5%) was "further medical therapy of no benefit"; "present quality of life is unsatisfactory" was answered in 19.1%. Alternative "C"—"If a new cardiac arrest occurs, further life quality would be unsatisfactory"—was given in 12.3% of the answers. There were 3 spontaneous answers: "parents asked for no more suffering," "refused ECLS," and "not a candidate for transplant."

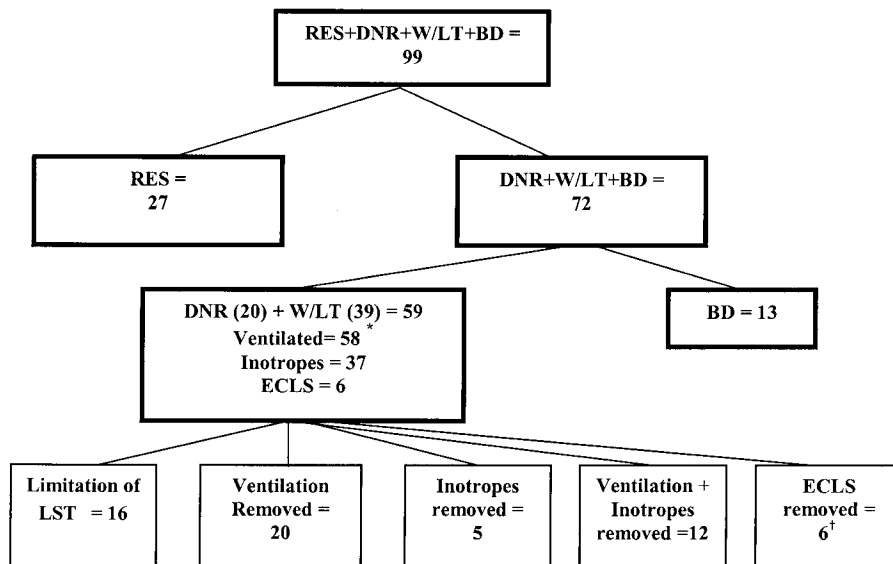
Methods of Therapy Withdrawal

Of the 39 W/LT cases, therapy was withdrawn in 82.1% (32); the remaining 7 patients had treatment withheld or not escalated (Fig 1). Within the DNR group, 55% (11 of 20) evolved to actually have LST removed. Hence, in the groups in which an end-of-life decision needed to be made, the practice at this center was actually to remove LST rather than just limit it in 72.9% (43 of 59) of all cases (ie, DNR and W/LT groups together). Of the 58 ventilated patients, terminal extubation as single method occurred only in 9 cases.

Interval Between the Decision to Forgo Therapy and Actual Death

Usually, DNR orders were written late in the patient's PICU course (mean: 6.9; range: 0.4–27.6; median: 4.1 day postadmission), except with 1 patient, who arrived in the PICU with a DNR in place. Generally, the time interval between decision and death was short in comparison with the entire LOS in the PICU. As described previously, 55% (11 of 20) of the DNR cases actually had withdrawal of therapy later in their PICU stay. The timing of the decision to limit or withdraw LST relative to death was available in 34 of 39 patients in the W/LT group. In this group, such a decision was also made late in the child's PICU

Fig 1. Patient groups and the end-of-life pathway. *One patient was not placed on mechanical ventilation. †One patient had ECLS not reinstated after a technical incident as a result of the child's cerebral injury diagnosed just hours before.



course (mean: 5.8; range: 0.2–36.6; median: 3.2 days). After a choice was made, it took less time for W/LT patients to die (median: 3 hours; range: 0.03–72 hours; mean: 9.1 hours) than the DNR patients (median: 24 hours; range: 4.8 minutes–6 days; mean: 38.8 hours; Mantel-Haenszel = 8, $df = 1$; $P = .005$). Once LST was removed, patients died within 0.5 minutes to 24 hours (mean: 80.3 minutes; median: 2.5 minutes).

A comparison between time of decision and death for the DNR and W/LT patients is presented in Fig 2. Within 12 hours of the decision time, 15% of the patients were still alive in the W/LT group compared with 58% in the DNR group.

Family Presence at the Time of Death

The family was present in 76.3% (45 of 59) of cases when therapy was withdrawn or limited, with no difference between DNR and W/LT groups. Among these 45 cases, in 77.8% (35 of 45), a family member or a guardian held the child at the time of death. Six (46.1%) patients in the BD group were organ donors and extubation was done in the operating room, so the families' final moments with their children were in the PICU.

DISCUSSION

This study confirms many previous observations about deaths within a PICU, and adds some details of value. A strength of this report is its prospective nature, because many previous articles were based on retrospective chart reviews.^{3–6,16,29,30} Such studies may suffer from recall and interpretation bias.⁹ Potential limitations of this report are the possibility of “responder bias,” as a result of the emotional nature of these encounters and the possibility of recall bias when the main investigator had to interview the staff (13 of 99 cases). This study is somewhat similar to an investigation by Burns et al,¹¹ who used a survey tool to evaluate prospectively end-of-life practices in 3 hospitals of a large metropolitan area in the United States. However, we examined additional aspects of this process, such as the presence of other PICU caregivers in the formal meetings with families, as an indicator of their participation¹³ and the families' attendance at the bedside at the time of death. Fur-

thermore, we explored the level of difficulty in achieving consensus with families about forgoing LST using the number of formal meetings as its surrogate.

Modes and Time of Death

It is known that 30%^{4,6} to 60%^{5,11,30,31} of deaths in a PICU follow decisions to forgo LST. The mode of death distribution found in this study is comparable to other pediatric series published during the past decade.^{3–6,10,16,29–32} This survey revealed that with the exception of 1 case, the physician responsible for writing DNR orders was actually the intensivist, frequently a stranger to the families, rather than the child's referring physician.^{7,33–35} The patients in the study who had LST forgone were older and had a longer PICU stay.¹¹

The end-of-life process more frequently involved LST removal, because only 18% (7 of 39) of the W/LT group had limitation or no escalation of therapy as the mode of choice. We did not routinely perform the Pediatric Risk of Mortality³⁶ score in our PICU at the time of the study; therefore, we cannot comment on whether withdrawal or limitation of LST was responsible for a more rapid death or this population was more severely ill than the DNR patients. Although not a universal finding,^{11,37} higher admission Acute Physiology and Chronic Health Evaluation III, Simplified Acute Physiology Score II, and Pediatric Risk of Mortality scores have been reported for patients with limitation of LST compared with patients with other modes of death.^{7,9,38} The short time interval between withdrawal of LST and death (median: 2.5 minutes) may indicate how gravely sick these patients were at the time or simply how dependent they were on the support measures being used.

Why and How Decisions Are Made

Previous studies have shown that neurologic impairment is 1 of the major reasons to forgo LST.^{4,10} In contrast, our survey showed that the majority (two thirds) of our patients did not have severe neurologic impairment as the main reason for having LST forgone. The intensivists did not indicate this, and the list of final diagnoses did not support it. Thus, in such cases, physicians must base their decision on factors not related to the possible future impairment of the intellectual or mental ability of the child. Expectation of imminent death is the main rationale for pediatric intensivists' forgoing therapy.⁷ It is certainly different from quality of life (which was an option) and poor prognosis,⁹ both factors quoted by adult clinicians^{39,40} and some neonatologists.⁴¹ In our survey, “lack of benefit from further therapy” was the most common reason given. Pediatric intensivists may be more comfortable with the justification of lack of “physiologic benefit” or “disproportionate burden”¹⁵ from additional therapy, when death seems imminent and yet so difficult to predict accurately.³¹ In contrast, for parents, issues such as quality of life, likelihood of improvement, and perception of their child's pain are the predominant decision-making factors.⁴² A survey among physicians and

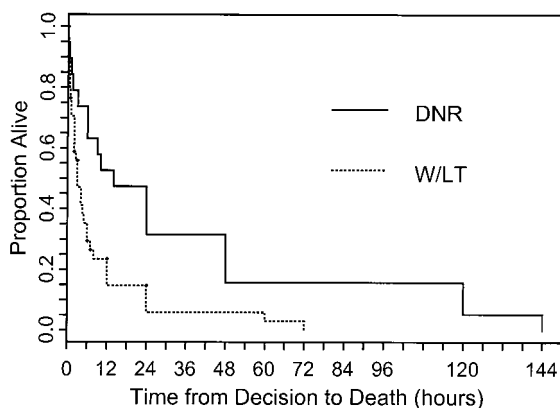


Fig 2. Times from decision to death for W/LT and DNR groups ($P = .005$).

nurses with hypothetical case scenarios revealed that family preferences, probability of survival, and functional status are the major determinants influencing decisions about restricting life-support interventions in pediatrics, although there are markedly different attitudes depending on who is in charge of the patient.⁴³

Our survey clearly demonstrated that decision making at the end of life in the PICU is a dynamic process.^{31,33,37,39,44} In almost half of the W/LT group, limitation in the level of support was considered in the earlier stages. Subsequently, 1 or more modes of LST were actually withdrawn. In the DNR group, approximately 50% of the cases evolved from DNR to active withdrawal of LST. Nevertheless, the patients were maintained as DNR to demonstrate that a DNR order might be the first step in a process that is subject to frequent reevaluations of its goals. It seems to be easier for the families to agree initially with limitation rather than active withdrawal of LST. However, as time passes, the clinical situation in some cases may become increasingly more difficult for both the families and the staff.⁷ Therefore, waiting and watching is no longer a good option.⁴⁴ This extra time, however, may allow the families to come to terms with their child's inevitable death, a period needed for acceptance. Keenan et al⁹ demonstrated the same pattern in their survey involving adults. In another Canadian study, 96% of adult patients were first classified as DNR, then vasopressors were discontinued, and finally mechanical ventilation was terminated.³⁷

Approaching the Families

Talking to families or surrogates about these issues is very challenging to most physicians.⁴⁵ Only 41% of the patients in the SUPPORT study engaged in discussions with their physicians about CPR, and in 80% of the cases, physicians misunderstood the patient's preferences.⁴⁶ Frequency of physician communication with families⁴⁷ and the quality of information given keeps arising as a significant problem for relatives of dying patients in intensive care,⁴⁸ although in 1 pediatric survey 70% of parents believed that they were well informed.⁴²

The intensivist is still most likely to initiate formal discussions about forgoing care, not the family.^{6,7,9,29,42} Approximately 30% of our families raised the issue of forgoing LST themselves compared with 44% in a study from the 1980s⁴ and 16% found in a multicenter study involving 16 PICUs.⁷ Meyer et al⁴² reported that up to 45% of parents had considered the possibility of limiting therapy before discussing it with any staff member. We speculate that the high number of families initiating the process in the late 1990s may reflect a shift from a somewhat more paternalistic medical attitude to a more family-centered care philosophy in pediatric institutions.¹⁷ Underlining the principles of autonomy and informed consent,⁴⁹⁻⁵¹ the present environment allows families to be more confident in expressing their wishes and thoughts. Hence, families may already have a clear position about their opinion before a formal discussion takes place. In large academic pediatric

centers such as the HSC, it is also not uncommon to "push the envelope" in complex patients.⁵² Such cases can generate a variety of different views within the multidisciplinary health care team about how to proceed, and this may delay some decisions.^{1,34,40,53,54} Consequently, the families feel compelled to voice their choices.

Our nurses' participation, although judged only by their presence in the formal meetings, was higher (75%) than has been reported in adults (16%)^{9,38} and in 1 recent French pediatric study.¹⁰ This may indicate either the good physician-nurse relationship existing in the unit or the different nature of the bedside relationship between nurses and families in a PICU compared with an adult ICU.^{48,55,56} Nurses normally engage in bedside discussion with parents about these issues long before there is an opportunity for the physicians to have formal meetings with them.^{31,42} Optimally, the nursing staff should be involved in all of the steps of the decision-making process.¹⁷ Burns et al⁵⁷ demonstrated that nurses are less likely to agree that families are well informed and ethical issues are well discussed when asked about their PICU's practice. One deficiency of our study is the lack of feedback from nurses and physicians about their views regarding the adequacy of the end-of-life care provided in each case in which they participated. We also did not characterize the level of participation of nonmedical personnel during our meetings. The Boston study revealed in their population a high rate of agreement between physicians and nurses on decision making and satisfaction with patients' treatment.¹¹ The residents' presence in the formal meetings was poor and needs to be encouraged.³³ Family conferences about end of life should be seen as an effective⁵⁸ "teachable moment" for staff in training.^{59,60}

In 50% of the cases, 2 or more formal meetings with families were necessary to reach consensus about forgoing therapy, perhaps indicating a more complex process or the existence of different goals regarding additional management.^{7,9} Moreover, in 1 BD case, consensus was never reached; thus, the patient died without receiving CPR. In a multicenter PICU study, most orders to restrict LST were written on average after 2 meetings with the families or surrogates.⁷ Likewise, approximately half of the families in adult studies would agree immediately or after only 1 meeting.^{9,40} When 4 or more gatherings were held before a consensus was established, a lower admission Acute Physiology and Chronic Health Evaluation II score and a trend to a longer adult ICU stay were found.⁴⁰ Breen et al⁶¹ reported conflict between staff and families in 48% of end-of-life discussion, and nearly 50% of families in another survey reported some form of conflict during their family member's stay in the adult ICU.⁴⁸ The similarity between the difficulties to achieve consensus with relatives of adults and children in the ICU is somewhat surprising, considering the differences in expectations about life span and family dynamics between these 2 patient populations.¹⁷

We could not detect an association among socioeconomic status, ethnicity, and disease category on

admission to the ICU with the number of meetings held. The correlation found with religious background is an important fact^{49,62} that has not been clearly shown in this context before, except in BD cases.⁶³ Additional studies are necessary to substantiate this finding. It has been demonstrated that even physicians, whose preferences' play a pivotal role in such decisions,^{34,53} may express diverse approaches to end-of-life decisions^{34,35} on the basis of their own religious background and country of origin.^{43,53,55,64,65} Within multicultural societies such as ours, understanding the patient's values and ethnocultural and religious traditions may improve end-of-life care by reducing the risk of conflicts and allowing more individualized care.^{49,63,66–69} A model for the proper use of LST in the ICU and for conflict resolution has been adopted recently by the HSC, which involves a negotiation and mediation model in a stepwise manner.⁷⁰

It is noteworthy that even in patients with BD, 38% of them presented a challenge when it came to the removal of support. The disease process, the acute nature of the event that led to BD,⁷¹ and perhaps the concept of BD itself could explain this finding.^{63,65}

Level of Support and Comfort Measures

When it becomes evident that cure or acceptable quality of life is no longer possible or expected, the focus of care changes from prolonging life to ensuring a dignified death.^{17,46,72–77} Previous studies in adults have reported a worrisome degree of treatable pain in dying patients.^{46,78,79} However, a recent family satisfaction survey in Canadian adult ICUs revealed that surrogates were satisfied with the pain management received for their loved ones.⁴⁷ In our population, analgesia with morphine was used in almost all W/LT cases as described previously in neonates⁸⁰ and adults.⁸¹ Increase in infusion rate occurred in <20% of our cases; furthermore, only 13% (7 of 54) had anticipatory dosing of sedatives at the time of death. Unfortunately, we did not ask the intensivists to specify or to justify their approach regarding analgesic dosage or to report whether any level of discomfort was perceived; thus, we do not know whether we have achieved our objective. A parent survey revealed that 20% disagree that their children were comfortable in their final days in the ICU,⁴² which corroborates previous studies of many children with cancer reported to be dying in pain.⁸² The health care team seems to believe that they are doing a commendable job. Burns et al¹¹ showed agreement between nurses and doctors in 87% of their cases with respect to the medications that they used. According to them, it seemed that they were sufficient in ensuring patient comfort.

Similar to other studies,^{11,83,84} we also had 3 patients who were weaned from ventilation and extubated with orders still valid in the charts for intermittent doses of NMB or paralyzing agents. Their clinical conditions were such that death was imminent despite aggressive therapy. In our population, NMBs were clearly not administered around the time of forgoing LST. We believe that they serve no therapeutic purpose during withdrawal of LST. The

removal of ventilation was also not an attempt to determine whether the patient would survive, because the child's condition had failed to stabilize despite the use of maximal support and death was virtually certain.⁸⁵ The continuation of its use could be acceptable only by the disproportionate burden of continuing treatment while waiting to be sure that there was no residual effect still present.^{85–87} Recently, 3 editorials were written about this issue in a critical care journal. They followed the Boston paper describing the presence of NMB in 8 dying patients of 53 studied. This conduct, although controversial^{12–14,86,88–91} and not ideal, has not been uncommon in ICUs.^{11,81,83,89} The most recent guideline for end-of-life care from the Society of Critical Care Medicine Ethics Committee explored this issue. The recommendation is that removal of LST in the presence of paralysis is "reasonable when physicians 1) are highly certain that the patient would not survive separation from the ventilator, 2) proceed with careful regard for the patient's comfort, and 3) have concluded that the benefits of waiting for the return of neuromuscular function are not sufficient to outweigh the burden."¹⁷ Our patients certainly met these criteria.

The family's presence at the bedside is another important element in the dying process, which is not well documented.^{17,74} In a slight majority of our cases, a family member was present at the time of death after limitation or LST withdrawal. Many caregivers actually held their child while LST was removed, or they lay in bed with their dying adolescents. Unfortunately, we did not investigate why some people elected not to be there. Some prefer it that way, and their choice is respected in our PICU. Although an emotionally charged situation, the family presence makes the process a clear and open one, conveying the shared nature of the decision. In a neonatal study involving 4 ICUs in the Netherlands, parents of extremely premature newborns were present at the time of death in 89% of the occasions.⁸⁴

CONCLUSIONS

Most deaths in the modern PICU are not unexpected; they are preceded by a clear decision to limit or, more often, discontinue LST. Therefore, improved care at the end of life is paramount.

Because of the difficulties in accurately predicting the outcome for a particular case, patients tend to have a prolonged course in the PICU before an end-of-life decision is made. A formal consultation with the family ensues after the health care team perceives that prolonging treatment would be inappropriate and not beneficial. The final decision comes as a shared one, although the consensus is achieved with some degree of difficulty in a relatively high number of cases. Direct neurologic involvement is infrequently the main cause for forgoing therapy. After a decision is made, the majority of children will die within 48 hours, most likely from withdrawal rather than limitation of LST. Death occurs within the PICU, frequently with a caregiver at the bedside holding the patient.

Additional studies are still necessary to uncover

additional factors that may complicate this process of decision making. Our ultimate goal should be to make the unfortunate circumstance of a child's death within the PICU as humane and dignified as possible.

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Circumstances Surrounding End of Life in a Pediatric Intensive Care Unit

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