



REVIEW ARTICLE

A “good” death in a pediatric ICU: is it possible?

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Abstract

Objective: In the modern pediatric intensive care unit (PICU) physicians are often faced with the need to interrupt life-sustaining treatment (LST) and to allow children to die when no further treatment options are available. Consequently, the importance of palliative care has been increasing in this context. The goal of this review is to provide intensivists with guidelines to allow PICU patients to have a more dignified and humane death.

Sources of data: Medline was searched using relevant key-words, emphasizing the topic of death in the PICU. The principles of palliative care medicine were then applied to this context.

Summary of the findings: To ensure a dignified death for a child receiving palliative care in the PICU some important measures must be taken, such as: let the family participate in the decision-making process in an open and honest manner; allow family members to perform their religious rites and rituals; offer them moments of complete privacy; effectively manage pain and discomfort, especially at the time of removal of LST; and finally, let the family be present when LST is interrupted, if they so desire.

Conclusions: A child’s death following withdrawal of LST in the PICU can be humane and dignified if basic principles of palliative care are followed. This is especially important in an environment that is notorious for the use of complex technology and described by the general public as inhumane.

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*Someday, I’ll come to an end, of course,
then God’s will will be fulfill’d
Dyin’ will simply not matter anymore
the very devil’s in just ceasing to live.*

Mário Quintana

“It is the duty of all to watch over the dignity of the child and adolescent, preserving them from any inhuman, violent, terrorizing, vexing or coercive treatment. (...)”

Art. 18 - Statute of the Child and Adolescent¹

Introduction

What should a dignified, decent, or acceptable death be like for a human being? Contemporary medical literature has addressed this issue quite frequently with respect to adult patients.^{2,3} It is not uncommon also to come across this topic in the lay press.⁴⁻⁶

Over half of 11 million children worldwide who will die this year before they turn five years old - approximately six million - will do so because of diseases that can be perfectly prevented with simple measures such as oral hydration.⁷ These deaths are certainly dishonorable,

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unnecessary, and a cause for shame on society as a whole. It seems unfair to even discuss deaths in pediatric intensive care units (PICU) considering this context. In any given PICU in Brazil there are cases of children who die after a decision is made to forgo resuscitation or aggressive intervention;^{8,9} therefore, there is no way of avoiding this debate. It may have a direct consequence on the performance of health professionals and on the level of satisfaction of families regarding the medical care provided in PICUs, and perhaps even carries economic implications.^{10,11} In addition, "the right to a dignified death, in the presence of one's family, after all the available therapeutic resources have been tried" is set out in Article 20 of the Rights of the Hospitalized Child."¹

In view of the fact that end-of-life care involves excessive and inappropriate use of technology or life-sustaining treatment (LST), "palliative medicine" has been gaining momentum in the intensive care literature;¹²⁻¹⁵ until recently the topic was prominent only in oncology. In pediatrics, the issue is far more vital, but still underinvestigated,¹⁴ although the death of a child in western societies produces one of the most painful grieving processes.¹⁶ For example, there is some fear in the use of opioids for the control of pain and discomfort at the end of life,¹⁷ and in writing down what actually happened on the medical records, etc.⁹ A Canadian study has been recently published with the aim of establishing parameters and guidelines for intensivists on how to provide terminally ill patients in ICUs with efficient analgesia and comfort, without committing euthanasia or breaking any laws. The participants in this study, intensivists and coroners (representatives of the legal system) reached a consensus, but pediatric intensivists were excluded.¹⁴

In the present review, in order to illustrate our analysis, we will use the data collected from an investigation of 99 consecutive deaths in a PICU in Canada. This study gathered information on the circumstances related to the decision-making process of families involving withdrawal (WD) or withholding of the life-sustaining treatment (WHLS).¹⁸ Our aim in the present review is to determine a favorable environment for a dignified and humane death from the point of view of the family, patient, and medical staff. We do not intend to provide guidelines on the proper use of analgesics or sedatives or on how to withdraw LST, as this can be found in other reports.^{13,19-23} We will describe the general measures that can be easily adopted so that the death of a child, albeit devastating, will be honorable, humane, compassionate, and free of physical suffering. Is it possible then to have "a good death" in the PICU? It is difficult for intensivists to accept this, but allowing the patient to have a good death should give cause for satisfaction, since in some aspects, it is similar to saving a life.²⁴

This review, although noncomprehensive, aims at going beyond regional, cultural and socioeconomic aspects, basically following the principles established by UNICEF for a child-friendly hospital environment, according to the UN Convention on the Rights of the Child.²⁵ Our intention is to change the misconception that "our ICUs are modern temples of human suffering."²⁶

Source of data

By using the key words death, advance directives, assisted suicide, brain death, modes of death, withdrawal, withdrawal of care, withdrawal of treatment, DNR, parents, decision-making, palliative care, end-of-life care, foregoing life support, we searched MEDLINE for relevant articles and we selected those that best suited our target population, more precisely, ICU patients. To illustrate and reinforce our ideas, we reproduce part of the data obtained through a study on this topic, which has already been published.¹⁸ In addition, we cite studies published by the lay press, as well as those found in the Brazilian medical literature.

Findings

Not surprisingly, most deaths of hospitalized children are already expected

While attending a training course ("fellowship") in North America, the author of the present article was amazed at the routine practice adopted in the PICUs regarding the withdrawal of LST (WDLs). After a consensus between the family and the medical staff that the critically ill child has no chances of recovery, the intensivist gently, respectfully and humanely withdraws the patient from the life-sustaining treatments. The parents are invited to take part in the process. One of the parents holds the child in his/her lap, and the administration of inotropic agents is discontinued and/or the endotracheal tube is removed after a quick reduction in ventilation parameters. Analgesia (usually opioids) is used to maintain the child free of pain or suffering.

As a result of this "ethical shock", the author conducted a prospective study in the second half of the 1990s in the ICU of the Hospital for Sick Children, in Toronto, Canada, with the aim of investigating the deaths at that unit. Not only did we distinguish between the types of death (see classification below), but we also studied the circumstances that preceded the final agreement between the family and health professionals on what to do when medical treatment was no longer effective. The study also included an analysis of the level of analgesia and sedation, and the patient's final hours of life.

The modes of death are classified as follows:

- a. Death after resuscitation attempts- failed CPR;
- b. Do-not-resuscitate (DNR) order;

- c. Withdrawal of life sustaining treatment (WDLS) or withholding of life sustaining treatment (WHLS);
- d. Brain death (BD).

The complete results of the study are available in the literature,¹⁸ but we will outline here the most relevant data concerning the last hours of life of patients for whom forgoing LST orders were written.

Among the 99 deaths observed throughout eight months, 13 cases were classified as BD (accounting for 13.2% of the total, 13/99); 39 deaths followed WDLS or WHLS (39.4%) and 20 (20.2%) resulted from DNR orders. Only 27 (27.2%) cases were preceded by resuscitation attempts, that is, the deaths were not expected. Consequently, the other 72 (72.7%) patients died after a medical decision of no intervention (BD, DNR, WHLS) or removal of ventilation and/or inotropic therapy (WDLS) (Table 1).

Therefore, more than half (59, 59.6%) of the patients died after a specific decision made by the family and medical staff, not including BDs. These results do not apply to this intensive care unit only, but they reflect what occurs in many other units in North America²⁷⁻³⁰ and in other countries as well (see Table 1).^{31,32}

In Brazil, a recent retrospective study carried out in Porto Alegre revealed that of the 44 deaths observed, 18 (41%) were classified as having restrictions of LST, as they resulted from WDLS, WHLS and DNR. This prevalence is still low if we consider that these cases seldom account for less than 60% of deaths in North America (Table 1).

A serious problem that prevents researchers from knowing what actually occurs in Brazilian ICUs is the so-called "untruthful records", as demonstrated by Torreão et al. in São Paulo. In a prospective, exploratory, and observational cohort study, the physicians who attended to

176 cardiopulmonary arrests (CPA) in one year were interviewed. Later on, the authors revised the medical records in order to cross-check the information. A total of 26.7% (47/176) of CPAs included no-CPR. Forty medical records of unresuscitated patients were evaluated. In 27.5% (11/40) the description was only "state that the patient died", while in the remaining 72.5% (29/40) it read "failed resuscitation attempts". The authors concluded that untruthful records exist for fear of possible lawsuits over the medical decisions taken, what is considered to be beneficial to the patient from the ethical standpoint.⁹ However, this practice is unjustifiable, as stated by the authors of an editorial on the article mentioned above.¹⁷

A recent multicenter study covering 457 deaths in PICUs in Argentina (Table 1) has revealed prevalence rates of 16%, 20%, and 11% for DNR, WDLS or WHLS, and BD,³³ respectively, in which 52% of the patients died after CPR attempts. This confirms the authors' impression that the number of cases in which LST is forgone is lower than that observed in North America,³³ accounting, nevertheless for more than one third of the total amount.

In short, one may affirm that even in Brazil, many cases of ICU deaths occur as a result of no intervention or removal of LST, in such a way that the surprise factor is more of an exception than a rule.

The decision-making process

The time of truth inevitably comes when both the medical staff and the family need to make a decision, allowing the patient to die a dignified death, without further life-prolonging procedures. Obviously, the decisions of parents and family members are hinged on their moral and religious principles. These principles vary from family to

Table 1 - Modes of death (%) in PICUs*

Place	WHLS or WDLS*	Brain death	DARA
Washington - USA ²⁸	32	30	38
Salt Lake City - USA ⁹⁵	58	23	19
Chicago - USA ⁹⁶	30	24	46
Edmonton - Canada ²⁹	49	22	29
Toronto - Canada ¹⁸	59.3	13.3	27.3
London - England	65	17	18
Lille - France ⁹⁷	28	38	34
Porto Alegre - Brazil ⁸	41	34	25
Argentina ³³	36	11	52

* Withholding of life sustaining treatment includes DNR in this study.

Abbreviations: WDLS: Withdrawal of life sustaining treatment, WHLS: withholding of life sustaining treatment, DARA: Death after resuscitation attempts- failed CPR, DNR: Do-not-resuscitate order.

family, and there is no magic formula for coming to a consensus on how and when to withhold or withdraw LST.³⁴

The intensivist should get a clear idea about the expectations and convictions of the family from the relationship established with them during the PICU course. According to Piva and Carvalho, it is essential that "the family follow the same reasoning as the medical staff in order to understand the present stage of the patient's disease".³⁵ More often than not, this requires time, a longer time than the medical staff can offer, as well as a larger capacity than the ICU allows.³⁶ It is known that patients designated as DNR or WD/WHLS have a longer PICU length of stay.^{30,37} DNRs were written on average 6.9 days after patients were included in our study. Only one patient had the DNR written by the specialist who referred the case to the PICU.

It is not the aim of this review to show how to reach a consensus or how to solve conflicts, but as we firmly believe there is no room for a totally paternalistic medicine that excludes the family from the decisions regarding ICU patients, we will discuss some basic aspects concerning the relationship between the family (parents or surrogates) and the medical staff in the decision-making process.

What families tell us

There is still a paucity of relevant studies in the medical literature on the opinion of families about the end-of-life care provided to their loved ones at the ICU, especially in pediatrics.³⁷ However, the issues brought up by most studies, which seem to correlate positively with the satisfaction with the care provided, are as follows:

- being included in the decision-making process;
- avoiding protracted death;
- receiving clear explanations about the role of the family;
- getting help in order for the family to reach a consensus;
- and receiving proper amount of good-quality information at the right time.³⁸

Abot et al. interviewed families that had recently lost a loved one at an adult ICU and reported that families regarded pastoral care and previous discussions about individual preferences for end-of-life treatment options as a source of psychological comfort. Relatives complained that there should be one single physician to whom they could go and talk. Some simple things like having a family conference room and lenient visitation times (open visitation) were some of the positive aspects mentioned by the interviewees.³⁹ A leaflet with explanations about what an ICU is like and how it works may play a pivotal role in the understanding of treatments and in the satisfaction of families with the care provided in the ICU.^{40,41} It should be underscored that the attitude of health professionals towards critically ill or dying children in the ICU, as well as towards their family, and the kind of information these professionals provide may

have a direct effect on the ability of the bereaved family to adapt to the loss of their loved one, and to go through a more appropriate grieving process. Parents who perceive some emotional detachment or disregard from the ICU team usually show inadequately early and long-term grief.⁴²

Meert et al. interviewed families - a total of 78 caretakers of 76 children - in a group of 157 patients who died in a PICU of Detroit (USA), asking them about their level of satisfaction with the forgoing LST decision-making process and the overall PICU care. On a scale of 1 (poor) to 5 (excellent), only 14% of the parents rated PICU care as ≤ 2 . These parents reported having difficulty understanding their child's clinical status, and also said they were not given proper attention. These cases were characteristically acute, in opposition to children who died from chronic diseases, whose parents showed a higher level of satisfaction. Eighty percent of the parents found they took the right decision about their child's life, 10% regarded their own decision as wrong and 10% did not know. Most parents (68%) said they received enough information before they could make a decision, and 56% affirmed they had enough time to make their decision. When asked about "who took the final decision about forgoing LST", 49% said that they themselves did, 29% said the doctors took it, and 15% said parents and physicians took the decision together.³⁷

A constant cause for frustration for families who lost a child in an ICU is that "nobody sat down and explained to them that their child was actually dying." Vague words such as "he might not recover anymore" are deceitful and only give false hope. If the family clearly gets the message that their child is dying, they will have enough time to bid farewell, contact distant relatives, ask about things that are more appropriate at this stage, and get prepared for the death and bereavement.⁴³

In view of the emphasis North American doctors lay on autonomy and "informed consent," families play a key role in the decisions involving their loved ones.^{37,44-46} In the PICU in Edmonton (Canada), families are invited to stay at the bedside even during the daily medical rounds made by the attending physician, resident doctors, pharmacist, nutritionist, nurses, and respiratory therapist (Figure 1). This has become so common that parents actually plan their visit to coincide with the medical rounds so that they can hear what the staff has to say, listen to their decisions and also take part in the discussions. Visiting policies are more lenient, only restricting the number of visitors allowed at a time. This allows an open, clear, and honest relationship between the involved parties. Free visiting hours are common practice in many neonatal ICUs in North America and also in North European countries.⁴⁷ This is part of the philosophy adopted by pediatric centers called "family-centered care"^{22,48} Cuttini et al. describe the practices in several European countries regarding visitation and participation in the decision-making process in neonatal ICUs. The percentage of units that allow unrestricted visitation ranged between 11% in Spain and 100% in Great Britain,

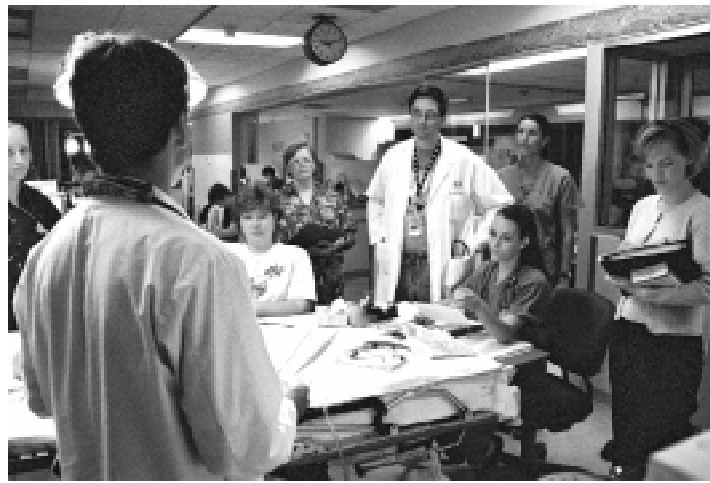


Figure 1 - Daily medical rounds in the PICU with the presence of patient's family members (mother sitting in a central position). (PICU, Stollery Children's Hospital, Edmonton, AB Canada - with informed consent)

Luxembourg and Sweden. The percentage of neonatal ICUs that explicitly allow the participation of parents in the decision-making process as to the life of their babies ranged from 19% in Italy to 89% in Great Britain.⁴⁷

What is the situation in Brazil like? It is necessary to investigate this in our PICUs. The fact that the Brazilian families we deal with have a low income, poor level of education and are partially illiterate does not justify the paternalistic attitude and the policy of secrecy maintained by many of our ICUs. Canada, and other countries subject to great waves of migration and with a high number of indigenous people, also presents this demographic profile and nevertheless adopts this family-centered philosophy. Certainly, these lenient rules on the access of family members to the ICU and on their participation in the decision-making process call for a trained medical staff, including assistance from social service and pastoral care, in addition to the strong commitment of PICU directors and support from hospital managers.⁴⁷ In general, the medical and nursing staffs are the main obstacle to the implementation of these new initiatives.⁴⁹ Until recently the father figure was not allowed in delivery rooms; today this practice is encouraged. The document "The Child Friendly Healthcare Initiative: healthcare provision in accordance with the UN Convention on the Rights of the Child" outlines the problems found in the separation of a child from his/her family, inhumane treatment of children, etc. and proposes specific measures to correct these problems. Among these measures it has the participation of families in the decision-making process.²⁵

Conflicts between the medical staff and families

Several factors may explain the conflicts that arise between families and the medical staff surrounding end-of-life decisions.

Breen et al. found conflict between the medical staff and families in 48% of the cases in which the issue of forgoing LST was discussed⁵⁰ and nearly 50% of the families in another study revealed that some kind of conflict existed during the stay of a family member in the adult ICU. These conflicts were mainly related to the health team's behavior, especially to their negative attitudes.³⁹

In the study conducted at the Hospital for Sick Children we used the number of formal meetings between the medical staff and family members as one of the indicative signs of conflict, following a model previously described in the literature.⁵¹ A consensus about the ultimate fate of these patients was achieved by families or surrogates after a formal medical conference in 49% (35/72) of the cases (including brain-dead patients). However, two meetings were necessary in 16.7% (12/72) and several meetings were needed in 26.4% of the cases (19/72). No consensus was reached in two cases only. These children died after a unilateral DNR decision taken by physicians, which was not contested by the parents. This piece of information was not obtained in four cases.

In a multicenter PICU study, most restriction of LST orders were written on average after two meetings with the families or surrogates.^{51,52} In studies with adult

patients, approximately half of the families agreed with forgoing LST immediately after one single meeting.^{51,53} When four or more meetings were necessary before reaching a consensus, this group showed a lower APACHE II score at admission - denoting more severe cases - and a tendency towards a longer ICU length of stay.⁵³ Our study design did not permit determining whether the parents or surrogates needed longer time to come to terms with the imminent death of their child,²⁴ as the rationale behind the need for more meetings. Regardless of the cause, these situations were interpreted as instances in which a consensus could not be easily reached. The similarity between the difficulties in reaching an agreement with family members of pediatric and adult ICU patients in half of the cases is somewhat surprising, given the differences in life expectancy and family dynamics between these two populations.²²

In 58% (7/12) of BD cases in our study in Canada it was very difficult for the families to permit the withdrawal of life-sustaining support or of vasoactive drugs at the first formal meeting. The acute nature of the event that leads to BD⁵⁴ and perhaps the definition of BD per se might explain this finding,^{55,56} which we empirically consider to be similar in the Brazilian context.

Among the various factors that could create conflicts, religion was the only one that showed predominance in our study. For instance, it was much easier to come to a consensus about DNR with protestant families than with Hindu ones ($p = 0.028$). The correlation with religion^{57,58} was not previously demonstrated within this context, except for cases of brain death.⁵⁶ Interestingly enough, families that profess religious beliefs seem to resolve their grief earlier than individuals with no religion.⁵⁹ Even physicians can have different opinions in life-or-death decisions depending on their religious background and country of origin.^{3,31,60-62} In multicultural societies, the understanding of patients' values, their religious, ethnical and cultural traditions can improve the attention given to families of ICU patients by reducing the risk of conflicts and allowing more individualized decisions.^{24,56,57,63-65}

Another reason for conflict is the difference of opinion between the health professionals, which could be perceived by parents.^{3,66} A recent multicenter French study revealed that 73% of interviewed physicians were satisfied with their end-of-life decisions in the adult ICUs, but only 33% of the nurses reported having the same level of satisfaction.⁶⁷ For that reason, it is important to include different medical staff members in regular meetings with the families, consult with colleagues, and contact the hospital ethics committee in the cases in which a consensus cannot be reached.

How could we solve these conflicts? A model for the correct use of life-sustaining treatment and resolution of the conflicts surrounding end-of-life decisions was adopted by the Hospital for Sick Children and by the University of Toronto, including scheduled negotiation and mediation strategies. This protocol is available in the literature.⁶⁸

Management of pain and other symptoms

When a cure or acceptable quality of life is impossible or unachievable in the opinion of the family and medical staff, the focus of ICU care must be changed. The goal is no longer to prolong life, but to guarantee the patient will have a dignified death that is free of pain and discomfort,²² by applying the principle of nonmaleficence.³⁵ Several studies such as that of the SUPPORT group conducted with adult patients⁶⁹⁻⁷³ revealed a level of discomfort and pain in terminally ill patients that is intolerable in modern palliative medicine.⁷⁴ This is what some Brazilian authors call *dystanasia*, that is, to maintain life at the expense of great suffering caused by useless or inappropriate treatments.^{17,35}

Some signs exist that this tendency is subsiding, as indicated by a Canadian multicenter study carried out in adult ICUs, in which families were asked about the patient care provided. The answers showed a high level of satisfaction with pain management in the ICU.³⁸ Nevertheless, a lot more has to be achieved in this area, as families have pointed out.⁷²

What about the children? A survey conducted with parents showed that 20% found their children felt uncomfortable during their final days or on those days that preceded their deaths in the PICU.⁷⁵ This corroborates previous studies that report an unacceptable level of pain in children who die of cancer.⁷⁶

In our patient population, analgesia was used in nearly all WDLS and WHLS cases, more specifically in 52 patients, accounting for 88.1% (BDs were excluded from the analysis). Continuous morphine infusions are usually the treatment of choice for newborns, children and adults under "terminal sedation and analgesia". Infusion was increased in 11 cases (18.6%); in addition, only three children required an extra dose of sedatives (known as "anticipatory sedation") shortly before their death; on other occasions, other sedatives or painkillers were administered (WDLS group) in isolation or combined with morphine. Unfortunately, we did not request that intensivists specify or justify their choice regarding the dose of medication and did not ask whether medication had the expected effect; however, Burns et al. affirmed that nurses and physicians agreed in 87% of the times that the dose and type of drug used were enough to assure comfort to the patient in a study similar to ours, which included three PICUs in Boston, USA.³⁰

It is not in the scope of this review to give an in-depth account of therapeutic options regarding analgesia, control of nausea, dyspnea, constipation, drugs for terminal sedation and ways to wean patients from mechanical ventilation, which are considered palliative in a PICU. We recommend excellent reviews on this topic, as the ones carried out by Truog et al.,²² Levetown¹³ among others,²¹ in addition to the sources cited in the introduction of the present paper. Recent studies have underscored the importance of consulting with the palliative medicine service, concluding that this can reduce the number of medical procedures and make support to the families more promptly available.^{10,77}

In the arsenal of drugs there is certainly no room for neuromuscular blockade at the time of death. The Society of Critical Care Medicine in its latest consensus on "end-of-life care in the ICUs"²² is quite clear when it establishes that the use of neuromuscular blockade is only admissible at the time of death in extremely rare or special situations. One of them is when the patient is considered terminally ill and waiting for the drug to be completely metabolized and for muscular activity to return to normal is more detrimental to the patient and his family than the quick removal of LST.^{22,78} Even so, the family should be asked about whether they would rather wait for the effect of the paralytic agent to wear off or withdraw LST immediately under proper sedation.⁷⁹ In 11 of our cases (18.5%) a paralytic agent (in an intermittent dose) had been prescribed for the patients, but it was not used on any occasion after the removal of LST decision was made. All of these patients were in a premorbid state, and only three of them had to be submitted to terminal extubation. The consensus established between intensivists working in the adult ICU and Canadian coroners clearly states that paralytic agents and drugs such as potassium chloride should not be used in end-of-life care in the ICU, as they show the physician's true intention - euthanasia¹⁴ - and this cannot be permitted or tolerated.

Objectives of palliative medicine in the ICU or how to assure a "good death"

In the adult ICU, surveys conducted with terminally ill patients, physicians and family members revealed what an "ideal death" should be like. It would include the following:

- control of symptoms (death with no pain or physical discomfort);
- appropriate preparation for death, including religious rites and rituals, etc.;
- strengthening of family ties (opportunity to say goodbye to family, friends, and loved ones);
- opportunity to go over one's life and recall important moments;
- opportunity to solve unfinished matters (e.g.: last will and testament, sale of properties, telling the family about important documents and passwords);
- avoiding protracted death.⁷⁴

How can we apply this concept of "ideal death" to pediatrics?

Management of pain and physical discomfort

We exhaustively discussed this topic previously. Physicians have to clearly register everything that was discussed with the family in the patient's medical records, and answer the following questions about analgesia and terminal sedation:

- What is the patient's present state of health and what are the reasons why he/she was submitted to palliative care in the ICU?
- What is the objective of using "terminal sedation"?
- How will you assess or determine the level of pain, discomfort, or suffering?
- How will you escalate the dose of sedatives and painkillers, and why?

This way, there will hardly be future problems with the family or with lawsuits in cases of death following WD/WHLS.

Preparation for death - rites and rituals

How long will the child survive after WD/WHLS? This piece of information is very important as families can build up unrealistic expectations about the time of death. It is crucial to prepare them for the fact that the child might not die, or death might occur within minutes or even after several weeks, depending on a wide range of conditions related to the disease and to the patient's general status. In our study, death occurred on average 24 hours after DNR implementation, and three hours after WD/WHLS ($p < 0.05$). In reality, removal of LST was performed in 11 of 20 DNR cases, indicating that parents and the medical staff concluded that waiting was not the best option anymore,^{31,52} a tendency also described for adult patients.⁸⁰ Some of the children who have LST withdrawn will not die in the PICU. Parents have to be warned about that; the transition has to be properly prepared with the medical team in the units that will receive the patient.

Maybe infants or preschool children do not benefit directly from religious rites and rituals, but parents and family members will certainly find great comfort in knowing that they were allowed such an opportunity and that some rituals could be performed in the ICU.^{65,81,82} In our PICU, it is not uncommon to have medicine men with their herbal rituals. They receive guidance from hospital professionals as to the use of materials (no one would like to run the risk of a fire in the ICU!), and the social assistance and pastoral care have their rules previously established with these medicine men, as well as with other religious groups, and the ceremonies are performed without any problems. To older children and adolescents, religious observances can have a special meaning (see below).

Opportunity to go over one's life, recall important moments and say goodbye

One should not forget that any school-aged child can perfectly understand the meaning of death and could perceive his/her own death. After the age of 9-10 years, the definitive concept of death is formed, and the child may express his/her feelings verbally or through drawings, games, etc.⁸³ For that reason, the patient can and should be involved in the decision-making process and be

properly informed whenever his/her clinical status allows so. Consequently, it is necessary to have the collaboration of services such as social assistance, psychiatry and/or psychology, etc. in order to help the PICU team include the child or adolescent in the end-of-life decision-making process. In older children and adolescents, we can encourage parents to remind them of important facts such as family vacations by bringing pictures, videos, etc. and by inviting old and current schoolmates, friends and relatives to visit them in the PICU. In such difficult moments, physicians should never say something like "unfortunately, there is nothing we can do for your son/daughter". Quite on the contrary, there is much to be done! The most appropriate question physicians should ask at this time is "what else can I do for you in such hard times?"

Presence of the family

In our study, the family or loved ones were present at the time of death in 77% (45 of 59) of the cases, after DNR or WD/WHLS decisions. Brain-dead patients were not included in this group because their bodies were taken to the operating room for organ retrieval. Of note, among the 45 cases in which the family or close relatives were present, 35 (77%) held the child in their lap during the withdrawal of inotropic therapy and/or while he/she was weaned from mechanical ventilation or was extubated. In the study conducted by Meert et al., 65% of parents were present at the time of death of their children, and none regretted being present. On the contrary, among 27 (35%) parents who were absent, 17 regretted not staying with their child at the time of death. Only one family refused to stay with the child when invited by the medical team.³⁷

It is important to tell the family what may or may not happen during and after WDLS. Some reminders: ask the family members whether they would like to hold the child in their lap, or lie beside the adolescent. Explain that the child will not feel any pain, and that the medical staff will give medication for sedation and analgesia as much as necessary in order to guarantee the patient's comfort. Try to predict the questions parents may come up with, but are afraid or unable to verbalize. Allow as long time as necessary for goodbyes, visits and rituals. As Todres et al. put it, remember this is the last and special moment parents will have with their children, who represent all their dreams and hopes.⁸²

The mother of an infant who suffered brain hemorrhage while waiting for a heart transplant in our PICU, and had to be weaned from mechanical ventilation, and extubated while his mother held him in her arms, wrote the following:

(...) Nothing could prepare me for what I had to face. I am grateful for being allowed to stay with my son. It was a "transition", he died a calm and peaceful death. I feel comforted and relieved to know I could hold him in my arms until the moment he rested in God's arms (...)

Right to privacy and appropriate place

How about the most appropriate place for someone to die? It is common knowledge that nowadays most people die at hospitals, especially in well-resourced countries.^{2,84,85} For instance, in Australia around 55.6% of adult deaths in 1910 occurred at the patient's house, compared with 25% today.^{86,87} However, there is a clearly stated preference for spending the last days of life at home, instead of in hospital, surrounded by strangers and frightening equipment.^{6,88} Most children who die at hospitals do so in the ICU (either pediatric or neonatal),²⁷ which accounted for nearly 70% in our study. Wouldn't they prefer to be discharged from hospital and die at home?

If possible, the child should be offered the option to have LST modalities removed in a more familiar environment. It may be his/her own house, or the unit from which the child was initially transferred from, a place in which the family would feel more comfortable, with the medical team they have had closer contact with.^{84,89} Children may benefit directly, dying a less stressful death at home than at the hospital, and the sense of responsibility, control and independence of parents increases, possibly improving the grieving process.⁹⁰⁻⁹³ However, a country's economic and social reality might not allow transferring patients home. The lack of support families have to cope with when they return to their community is a constant problem, even in richer countries.⁷³ Other patients may not survive transportation.⁹⁴

The solution we found in our PICU was to turn one of the isolation rooms into a place for palliative care. The "room" has a different decor, background music, adjustable and adequate lighting, more comfortable furniture and space for many visitors. We hide the equipment behind curtains, and when we need the bed for usual patients, we open them. This ICU bed is the place for children who will receive palliative care and removal of LST (Figure 2). A similar option is offered by other centers, such as the "butterfly room" in Galveston, Texas.¹³ We have already performed WDLS in the hospital yard, as the family desired a natural environment where the child could be exposed to sunlight. Pets like dogs and cats are allowed in the PICU for short visits.⁸²

Families need total privacy at this time,^{36,82} respecting the patient's right to a dignified death. In this case, we remotely monitor the child through the PICU central station if the family would rather be left alone to say goodbye, but we regularly enter the room to check whether the child is comfortable.

Bereavement care - our work has not finished yet

After the death of a child in the PICU, parents feel abandoned and all alone. The medical team was part of their daily life, and suddenly they have all gone. The link has been broken!



Figure 2 - Palliative care and removal of LST room of PICU at Stollery Children's Hospital in Edmonton, AB, Canada

A bereavement group may give the families the support they cannot find anywhere else, helping them overcome the painful experience of losing a child. Some practical ways to attain this goal include meeting the family to discuss autopsy results, sending letters, birthday greetings, and Christmas cards, recommending specific books to help family members, calling regularly, and referring them to support groups or associations.⁸² Our bereavement group holds two memorial services a year in which all families that lost a child in that year can participate.

Conclusion

Many of the children who die at our modern hospitals do so in the ICU. Especially in PICUs, there are a considerable number of deaths that follow a joint decision made by the medical staff and the family to forgo LST. It is therefore essential to turn the final moments of these patients into a somewhat pleasant experience. Standard palliative care measures such as total physical comfort (not only absence of pain), not prolonging death, and the presence of the family are rights of the child at his/her time of death that must be respected. The multidisciplinary team can transform the PICU's unpleasant environment into a "temple" of compassion, humanization, respect, openness and dignity. Yes, dying a dignified death is possible!

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