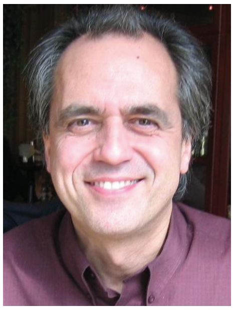
EDITORIAL

Improving end-of-life care in the pediatric intensive care unit



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The decision to forgo life-sustaining treatment is made for 20–55% of terminally ill children in North American and European pediatric intensive care units (PICUs) [1–3]. The management of children at the end of life (EOL) can be divided into three steps. The first concerns the decision-making process. The second concerns the actions taken once a decision has been made to forgo life-sustaining treatments. The third regards the evaluation of the decision and its implementation. Several guidelines have been published on these different steps [4,5]. However, each step raises its share of controversies and presents tremendous opportunities to improve EOL care in the PICU.

How the decision is made

Deliberation process leading to the decision

During the deliberation phase, the decision makers weigh up the benefits and burdens of medical treatments, taking into account numerous factors. Some of them are medical, such as factors influencing the prognosis, like the cause of the disease. Others are organizational, such as professional guidelines, training of the staff, and communication within the staff, with the patient and with his/her family. There are also factors relating to the patient's and family's wishes, their religion and social perspective. Finally, societal factors, such as cultural background or legal context, may affect the process. This nonexhaustive list shows that the decisional process is multifactorial, the relative importance of each factor being weighed in each individual case.

Decision makers

A controversy persists regarding the roles of parents and physicians in the decision-making process. In North America, parents are recognized as the main decision makers, in contrast to some European and South American countries where physicians assume this responsibility [2,6,7]. Between these contrasting perspectives, many countries have adopted the concept of shared decision making [8]. The aim is to build a collaborative relationship with the family and reach a consensus between parents and healthcare professionals. This points out the crucial role of communication – within the healthcare team itself and with the family. Parents need clear information from physicians about their child's condition, prognosis and alternative treatments. Regrettably, research findings suggest that physicians routinely overestimate what patients and family members understand [9].

Parents' perspectives

Factors influencing parents' decisions are their previous experiences with death and EOL decision making for others, their personal observations of their child's suffering, their perceptions of their child's will to survive, their need to protect and advocate for their child, and the family's financial resources and concerns regarding long-term care. Meyer *et al.* have demonstrated that parents place the highest priorities on quality of life, likelihood of improvement and perception of their child's pain when considering withdrawal of life support [10].

Children's perspectives

There is a growing recognition that the voice of the child should be taken into consideration [11]. In many legal jurisdictions, older children (e.g., 14 years and older) have a right to consent to treatment, whereas the assent of other children should be sought. Unfortunately, critically ill children are commonly unconscious, and therefore unable to participate in the decision-making process.

Physicians' perspectives

Factors influencing physicians' perspectives mainly regard outcome prediction, the balance between burdens and benefits, and the concept of futility. One of the most commonly used justifications for withholding 'high-tech' therapy from patients is the belief that 'extraordinary' treatments are futile. This question of futility remains largely

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unresolved. First, each patient's situation is unique and can not be compared with previous cases. Moreover, opinions on the value of life may differ. For instance, while some may value the preservation of life at all costs, others may conclude that the foreseeable quality of life is so poor that death is the preferred outcome. Some may see hope in an extremely small chance of success ('hoping for a miracle'), whereas others see a prolongation of the dying process. In other words, such futility claims are value-laden. It is, however, important to establish which interventions are physiologically futile (e.g., cardiopulmonary resuscitation for a 20-week gestation premature birth).

Nurses' perspectives

The involvement of nurses in EOL decisions is crucial [12]. The role of nurses can be described as managing the process and care of the dying child and guiding the parents in these difficult times. While providing care, nurses commonly develop a close relationship with the child and parents. The decision to withdraw or withhold life-sustaining treatment should always be based, however, on the complete overview of the patient's status and the family's perspectives. Nurses should take part in any EOL care discussion, even from the first discussion session onwards. Unfortunately, this collaborative practice is often a far cry from reality. For example, a recent survey among nurses and physicians in the adult intensive care unit revealed that nurses reported lower collaboration with physicians, resulting in higher moral distress and less satisfaction with care [13]. Regardless of who has to make the ultimate EOL decision, interdisciplinary collaboration is a must in any preliminary and ongoing discussions towards an EOL-care decision. Recognizing all of the PICU staff in this process can help ensure the most informed and ethically sound EOL decisions.

Implementation of the decision

The second step in the EOL decision-making process concerns the actions that are taken once a decision has been made to forgo life-sustaining treatments. This issue raises different ethical questions and moral dilemmas.

Withholding & withdrawing life support: are they ethically different?

Is there a difference between stopping a treatment once it is started and not starting it in the first place? In a survey including 110 physicians and 92 nurses from 31 pediatric hospitals in the USA, the statement that 'withholding and withdrawing life support is unethical' was not endorsed by any of the physicians or nurses [12]. More physicians (78%) than nurses (58%) agreed or strongly agreed that withholding and withdrawing are ethically the same. Nevertheless, this survey demonstrates that physicians are much more comfortable in withholding treatments than in withdrawing them. The underlying reasoning appears psychological in part. Physicians will feel more responsible for the death of a patient when it results from the withdrawal of a therapy, which will frequently hasten the child's death, than they do when it results from the withholding of a therapy.

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Nutrition & hydration: are they natural or artificial?

Many view nutrition and hydration administered through a medical device (e.g., enteral feedings) as a medical therapy, which can therefore be withheld or withdrawn like any other treatment on the basis of associated benefits and burdens [14,15]. However, some pediatricians are reluctant to accept the withdrawal of medically administered nutrition and hydration, at least in part because 'feeding' seems to be such a basic and fundamental need and aspect of the care that they should provide.

Sedatives & analgesics: what is the real intention?

One crucial issue is the doctrine of double effect. This doctrine states that when an action has two effects – one of which is inherently good and the other inherently bad – it can be justified if certain conditions are met. For example, the administration of morphine to a dying patient produces both a good effect (relief of pain and suffering) and the potential for a bad effect (hastening the patient's death through respiratory depression). The key difference between this practice and euthanasia lies in the intention of the physician. When the physician's intention is to hasten the patient's death, then the line between accepted practice and euthanasia is crossed.

Goals of care: where is the border between curative & palliative care?

The clinician's responsibility to the child and his/her family does not end with a decision to forgo life-sustaining treatment, but continues throughout the dying process. The emerging perspective is that palliative care and intensive care are not mutually exclusive options, but rather should be coexistent [5]. Thinking in terms of the goals of care for an individual patient can aid the physician in discussions with the healthcare team and the family when making or revising a management plan. The question then becomes how to best care for the patient during the dying process. Helpful recommendations on this issue have been published by the Ethics Committee of the Society of Critical Care Medicine [5].

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Needs of the dying child & family

Preparation of the patient and the family is based on a significant understanding of their needs. One can readily anticipate the fundamental needs of a dying child, such as to be with his/her parents and family, to have no pain, to have tender loving care, to respect his/her body and to respect his/her own and the parents' wishes.

Meyer *et al.* recently reported on the specific needs of parents whose children had died after the forgoing of life-sustaining treatment [16]. It appears that, in practice, pediatric intensivists do not always satisfy these needs. Clearly, the child and his/her family should know the identity of the attending physician, understand that this individual is ultimately responsible for the care and be assured of his/her involvement. In fact, most families consider clinicians' communication skills as equally or more important than their technical skills.

Family-centered care

Family-centered care is an approach to the planning, delivery and evaluation of healthcare that is grounded in mutually beneficial partnerships among healthcare providers, patients and families [17].

The family is acknowledged as an expert in the care of their child, and the perspectives and information provided by the family are important for clinical decision making. This requires a recognition of the family as a constant presence in the child's life that normally bears the responsibility for maintaining the child's wellbeing, to facilitate parent–professional collaboration, to share complete and unbiased information with families and to satisfy child and family needs. Parents should be viewed as partners in care, rather than visitors [18]. Parental participation in care can include holding the child's hand, speaking and reading or singing to the child, as well as assisting with bathing, positioning or massage.

Parental presence during medical rounds is encouraged in some institutions. On the other hand, many institutions are concerned that this practice will significantly increase the time spent rounding, and disrupt the usual workflow. Conversely, there is a fear that the presence of parents might inhibit open discussion among staff.

The presence of family members during cardiopulmonary resuscitation is also a controversial issue. Patients have the right to have family members present and parents should normally have the opportunity to be present during the resuscitation of their child.

Palliative care

In the curative model, the benefits of care are related to the degree to which the procedure will contribute to the patient's recovery from illness. In the palliative care model, the benefits are related to whether the intervention will improve symptom relief, improve functional status or ameliorate emotional, psychological or spiritual concerns [19]. The goal is to achieve the best possible quality of life for patients and their families. As previously mentioned, palliative care and curative care are not mutually exclusive options but rather should be coexistent, so that care – apart from life-sustaining treatment – is never withdrawn.

How we can improve end-of-life care

Quality-improvement procedures are important for evaluating the process of dying, just as they are for other hospital procedures. Interventions to improve EOL care in the PICU setting have been little researched. In a recent article, at least six relevant domains have been identified [20]. All offer tremendous opportunities to improve EOL care in dying children, knowing that bereaved parents are in a unique position to comment on current practice in EOL care [21]. Indeed, gaining an understanding of the perspectives of the family on the dying process is an essential step in understanding the quality of care provided. These domains include:

- Strong interdisciplinary collaboration and communication within the critical care team and with the palliative care specialists;

- Good communication skills of the team members;
- Excellence in symptom assessment and management, including pain, dyspnea, delirium and anxiety;
- Patient- and family-centered care focusing on the patient's and family's values and treatment preferences, as well as regular communication, psychological, spiritual and social support, and open 'visiting' policies;
- Regular interdisciplinary family meetings focused on shared decision making, as well as support for family members.

Conclusion

For a long time, research regarding EOL care in the PICU was descriptive and based on observational studies and surveys. It is now important to conduct systematic evaluations of healthcare professional's efforts to provide the required care to dying children. Such research is imperative toward supporting the efforts of healthcare professionals toward improving the quality of care for critically ill and dying children in the PICU.

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