Introduction

The pediatric intensive care unit (PICU) is a complex and often intense environment where a multidisciplinary group of clinicians apply a diverse range of cognitive and technical skills and resources in hopes of returning a critically ill child to an acceptable level of functioning or health. Fortunately, the vast majority of these efforts are successful. At other times, doubts can arise concerning the appropriate use of PICU technology given, for example, diagnostic or prognostic uncertainty, differing judgments about the acceptability of an outcome, or a perception of limited resources. Simply because we can intervene, should we? Such doubts when expressed can lead to disagreement and perhaps conflict among clinicians and family members. The potential for conflict, whether apparent or real, can be exacerbated by a compressed time frame, individual stress, the involvement of multiple clinical services, and so forth. At such times, careful ethical analysis combined with respectful listening and collegial communication is essential to help resolve the issues. This chapter discusses the ethical issues involved in setting limits on the use of technology in the PICU, including the use of medications and artificially provided hydration and nutrition. These issues are then set within the broader context of communication and conflict resolution. The chapter ends by highlighting several ethical issues raised in the context of organ procurement and research with critically ill children.

Setting Limits

Forgoing Life-Sustaining Medical Treatment

Most critically ill children recover and return to an acceptable quality of life. Some children either respond partially or fail to respond to life-sustaining medical treatment (LSMT), leading to death within minutes to years. In fact, most children who die in the PICU do so after a decision has been made to either limit or withdraw (i.e., forgo) some form of LSMT [1]. The use of LSMT assumes that the burden of treatment is justified by the anticipated outcome of an acceptable quality of life. As the anticipated quality of life deteriorates or becomes increasingly unlikely, or as the burden of treatment becomes intolerable, continued LSMT may not make sense. Decisions to limit LSMT may include not attempting resuscitation, not escalating inotropic or ventilator support, or not starting new treatments (such as endotracheal intubation or new modes of ventilation). Decisions to withdraw LSMT may include stopping inotropic support, decreasing or stopping ventilator support, stopping endotracheal intubation, or stopping artificially provided hydration and nutrition.

The reasons for forgoing LSMT can be grouped into two broad categories: the intervention either (1) does not or will not work (i.e., futility) or (2) is not worth doing as the burden of treatment outweighs any expected or actual benefit (i.e., disproportionate burden) [2]. For example, performing a tracheotomy and instituting long-term ventilation for a child in a persistent vegetative state who aspires and develops respiratory failure may be disproportionately burdensome, but it is not futile. The majority of decisions to forgo LSMT in the PICU are based on the judgment of disproportionate burden rather than on the more limited concept of futility.

The judgment that continued LSMT presents a disproportionate burden involves a complex and value-laden balancing between the burden of intervention and the benefit of the anticipated outcome for the child. In striking this balance, the focus should be on the quality of the child’s experience and not on the worth of that child’s life to others. Although pain and agitation can be minimized through medication, caregivers and parents may perceive differently the degree to which a child is suffering and to what purpose. The loss of interaction with a child who is on extracorporeal membrane oxygenation (ECMO) or nonconventional forms of mechanical ventilation because of the need for sedating medication may be especially difficult for parents. In conversation, clinicians should seek to understand the parents’ perspective and the role of factors such as tolerance for disability, hope for recovery, religious faith, views of other family members, and so forth.

Clinicians often use the term futility broadly and thus obscure the fact that the assessment of disproportionate burden rests on a value judgment about the anticipated outcome that the family may not share. As futility may be used to justify a decision to forgo...
LSMT absent parental agreement, an overly broad interpretation of futility inappropriately privileges clinicians’ values over those of the parents and family. The concept of futility should refer to only those interventions that will not in fact achieve a given physiologic outcome. An appeal to futility should not short-circuit the process of communication by which medical interventions are determined to be disproportionately burdensome [3].

**Disclosing “Bad News”**

Approaching a child’s parents to initiate a discussion about forgoing LSMT can be difficult. The perceived futility of a given treatment, which would otherwise be provided (e.g., attempted resuscitation) or is underway (e.g., prolonged ECMO for respiratory failure) argues in favor of initiating such a conversation. A reasonable starting point is to explore a parent’s hopes and expectations about possible outcomes, the anticipated burden of treatment in attempting to achieve an acceptable outcome, and the degree of uncertainty in predicting a child’s response to treatment. However, a recommendation to forgo LSMT before a family is ready to consider the options risks a loss of trust, a hardening of viewpoints, and thus damaging the working relationship with a child’s parents so necessary for shared decision making. Parents often prefer to hear difficult information from a clinician who knows the family and can communicate truthfully, clearly, and compassionately. Parents also may be more comfortable exploring initial doubts about on-going LSMT with someone other than the responsible physician [4].

The disclosure of bad news is often poorly handled. Parents may perceive a clinician to be indifferent and inconsiderate, resulting in emotional distress. Lack of training, inexperience, and feelings of inadequacy about communicating with parents over end-of-life issues may distress clinicians and impact negatively on the quality of care. Clinicians who feel less competent and inadequately supported may distance themselves emotionally in stressful situations, perhaps leading to depression and other symptoms [4,5].

**Do Not Attempt Resuscitation Orders**

The discussion of options for resuscitation in the event of either a respiratory or a cardiac arrest may be the first time that a parent has considered forgoing LSMT. The limitation of resuscitation efforts occurs in at least four broad contexts: (1) a decision to not attempt resuscitation (DNAR) is a necessary component of forgoing other LSMT (e.g., endotracheal extubation); (2) the patient is currently stable, but the future need for resuscitation would indicate that other interventions have failed; (3) the patient is currently stable, but the patient’s condition would make future resuscitation disproportionately burdensome; or (4) the patient is deteriorating and there are no other available interventions to reverse the process, including resuscitation.

Although DNAR orders are often discussed as part of a broader palliative care plan, the continued provision of all appropriate curative interventions is consistent with deciding to forego resuscitation in the future should these efforts fail. Health care providers often assume that the presence of a DNAR order indicates the desire to not pursue other interventions to forestall death. This assumption is inappropriate absent an explicit decision to this effect. Health care providers may also assume that the absence of a DNAR order obligates them to performing a prolonged resuscitation in a one size fits all manner. As long as the futility of initiating or continuing resuscitative efforts does not cloak a unilateral judgment about the moral value of a child’s outcome, a physician should tailor resuscitative efforts to the clinical condition of the child (including the possibility of not initiating resuscitation at all). Finally, the effectiveness and/or acceptable burden of specific resuscitative interventions may vary depending on the patient’s clinical condition and anticipated outcome. Thus, DNAR orders should address separately the provision of mechanical ventilation with or without endotracheal intubation, the use of cardiac medications, chest compressions, and cardioversion. A parent may want a focused resuscitation in hopes of sustaining a child’s life while acknowledging the unacceptable burden of more invasive interventions such as endotracheal intubation or cardioversion.

**Time-Limited Trials**

The widespread use of innovative treatments, the pace of technological change, and the lack of appropriately controlled clinical studies render uncertain many if not most predictions of patient outcome absent severe multiorgan system failure. Under such circumstances, the concept of a time-limited trial offers the advantage of assessing individual response to treatment and then withdrawing LSMT in the face of either disproportionate burden or futility. The time frame for evaluating the success or failure of such an intervention (e.g., ECMO for non-neonatal respiratory failure or following cardiac arrest) should be stated from the outset. Even so, parents may find it difficult to agree to the withdrawal of LSMT as this time limit approaches. For many clinicians, the continued provision of burdensome or futile treatment to a dying child may be difficult to tolerate. An important first step in trying to resolve such a situation is to negotiate with parents a limited time period for making a decision about withdrawing LSMT. The negotiation process will involve a difficult balancing of the patient’s best interest, the perceived burden of ongoing pain and suffering, and the parents’ hopes and fears for the life of their child. The clinician should strive for a mutually respectful and supportive relationship with the parents while maintaining open communication about these difficult issues.

The use of time-limited trials has been supported by the prevailing view that there are no moral or legal differences between withholding or withdrawing interventions that are not medically indicated. The perceived reluctance to withdraw interventions once started has often been attributed to emotional or psychological difficulties. The alleged symmetry between the application and removal of technology assumes that the technology itself is value neutral and that any other changes that may occur over time apart from the presence or absence of the medical indication for that technology are not morally relevant. Both assumptions may not be appropriate, especially when transitioning from an acute to a chronic technology [6]. If uncertainty remains about the ongoing provision of LSMT, one should exercise caution when transitioning to a surgically placed tracheostomy and/or gastrostomy tube. The transition to more intense forms of technological support such as ECMO following cardiac arrest usually occurs under great duress, limited time, and uncertainty. However, the ability of a child to survive for prolonged periods is limited under these conditions, and the pain and agitation of the child can be effectively managed with appropriate use of medications. As such, when escalating technological support, the consequences of a wrong decision, while difficult and troubling, are usually more contained.