Withdrawal of treatment in children

With advances in medical technology, many critically ill children will die following withdrawal of treatment rather than failed resuscitation attempts. Legally the parents are surrogate decision makers. The authors review the ethical, legal and practical aspects of withdrawal of treatment and the complex interactions between them.

Advances in medical technology have afforded health-care teams more strategies to sustain the lives of critically ill children. Previously, patients would die after the limited treatment options had been exhausted. More recently, a significant number of children are dying following the withdrawal or withholding of life-sustaining treatment (Burns et al, 2000; Wilkinson et al, 2006; Ramnaryan et al, 2007). This usually occurs when death is imminent, further treatment is futile or future prognosis is poor. Issues of patient competence and the role of the family in the decision-making process complicate the process in children. In addition, it involves ethical, legal and practical considerations that are intricately enmeshed but which must be reviewed as separate entities to understand how they interrelate.

Ethical perspective

The two primary ethical concepts to consider in the withdrawal of treatment are sanctity of life and quality of life. Clearly, respect for both sanctity and quality of life are guiding principles for physicians but are not absolute since they may involve subjective decision-making by both health-care teams and the patient. Indeed, these principles have been the focus of prolonged ethical debates. The framework document by the Royal College of Paediatrics and Child Health (2004) encapsulates the ethics of withdrawal of treatment in children. It outlines the five situations where withdrawal of treatment may take place (*Figure 1*). The document aims to guide professionals to act in the patient's best interest, in accordance with The Children's Act 1989. In doing so, health-care teams must strike a compromise between acting to benefit the child (beneficence) while minimizing any harm of prolonging treatment (non-maleficence).

Figure 1. Royal College of Paediatrics and Child Health (2004) guidelines.

Five situations where it may be ethical or legal to consider withholding or withdrawal of life-sustaining treatment:

The brain dead child	The child has fulfilled the criteria for brainstem death
The permanent vegetative state	The child is reliant on others for all care and does not react or relate with the outside world
The 'no chance' situation	The child has such severe disease that life-sustaining treatment simply delays death without significant alleviation of suffering
The 'no purpose' situation	Although the patient may be able to survive with treatment, the degree of physical or mental impairment will be so great that it is unreasonable to expect them to bear it
The 'unbearable' situation	The child and/or family feel that in the face of progressive and irreversible illness further treatment is more than can be borne. They wish to have a particular treatment withdrawn or to refuse further treatment irrespective of the medical opinion that it may be of some benefit

Dr T Vince *is Consultant Paediatric Intensivist, Kings College Hospital, London SE5 9RS and* **Dr A Petros** *is Consultant Paediatric Intensivist, Great Ormond Street Hospital, London*

Correspondence to: Dr T Vince

However, who decides the patient's best interests? In ethical terms, the patient him-/herself is the most appropriate person to decide this. However, a person's autonomy, or ability to determine the course of his/her life, depends on his/her competence. Competence arises from a person's cognitive ability and experiences and is the ability to assimilate information, apply it personally, and thereafter make an informed decision and understand the consequences of that decision. Therefore, during the acute phase of critical illness the patient may not be able to exercise his/her autonomy. Adult patients may well have expressed their wishes regarding end-of-life care through advance directives or informal conversations with relatives. This is unlikely to apply to critically ill children unless they have suffered from a chronic or terminal illness (Himelstein et al, 2004). Furthermore, a child's autonomy is limited paradoxically by his/her burgeoning competence.

Under these circumstances, doctors will look to the child's representatives to act as decision makers. This is usually the child's family who love the child and are devoted to his/her best interests. In addition, they share the child's beliefs and values and therefore will approximate the child's wishes (Sklansky, 2001). However, emotional stress or conflicts of interest sometimes prevent parents acting in the child's best interests (Allmark, 2002; Gladsjo et al, 2004). In contrast, doctors may be more experienced and objective regarding the natural history of the child's condition. However, the General Medical Council guidance (2002) states doctors are not ethically obliged to provide any treatment they believe is not beneficial to the patient and, indeed, are ethically obliged to avoid such interventions.

Hence, albeit motivated by beneficence and non-maleficence, physicians may impose on the family their personal values and interpretations of the child's best interests (Lee et al, 1991; Burns et al, 2000; Sklansky, 2001). As such, neither party may act in the way the patient wishes (Farber et al, 2006; Shalowitz et al, 2006) and an independent third view may be required.

Legal perspective

There have been a number of legal rulings which guide physicians in these difficult decisions while trying to include ethical principles. The issue of a child's autonomy and competence has been the subject of much high-profile legal debate. The Gillick ruling in 1985 stated that a child deemed competent could consent to treatment [Gillick v West Norfolk and Wisbech Area Health Authority 1985] but later judgments ruled that regardless of his/her competence, a child under 16 years of age is not able to refuse treatment and could be overruled by parents and doctors [Re J 1991]. Thus it appears that we may accept a child's ability to consent to treatment but deny him/her the ability to refuse the same treatment. Nevertheless, the legal position means that the child's representatives are effectively responsible for his/her best interests and must be consulted in any decision regarding withdrawal of treatment.

Ascertaining who can represent the child's interests is not an uncommon consideration in paediatric practice. Legal responsibility will normally fall to the parents. If the biological parents were married at the time of the child's birth, both mother and father will share parental responsibility. If they were not married, the mother alone has parental responsibility, unless the father obtains a court ruling permitting him shared responsibility. Occasionally, the Court may appoint other persons as legal representatives for a child who then may act on the child's behalf. This issue can be resolved by discussion with relatives, and clearly it is vital that the child's legal representatives are correctly identified and participate in all discussions.

Several legal cases including Re J [1991] have given considerable weight to the preservation and prolongation of life. If a physician goes to court to suggest the opposite, a heavy burden is placed upon him/her to persuade the court to make a declaration which will effectively lead to the end of a person's life [Re K 2006]. In addition, the Glass case in the European Court of Human Rights [Glass v United Kingdom 2004] highlighted that, where disagreements arise, health-care teams are expected to refer the case for legal arbitration. Consequently, it suggests that health-care teams and the child's representatives should endeavour to reach agreement on end-of-life care. If decisions are made without proper recourse to legal ruling, this may lead to criminal investigations.

Practical perspective

Where disagreements between the health-care team and parents arise, it is sometimes helpful for teams to refer the child for opinions from a second medical team, a medicolegal adviser and occasionally a local ethics committee. Nonetheless, it is clearly desirable for the health-care team and parents to agree on the most appropriate strategy for end-of-life care. This entails multiple and honest communications with the family that are discussed and planned by the health-care team to ensure consistency. Furthermore, it is crucial that health-care teams determine how much responsibility the parents wish to take for withdrawal of treatment decisions. Some parents find the responsibility too great and the health-care team may have to adapt accordingly. At the time of withdrawal, it is particularly important to explain that the likely outcomes including terminal gasping and even that the child may continue to breathe for some considerable time.

The use of sedation in these circumstances may prove helpful as this may relieve terminal gasping, pain and anxiety. Sedation doses should be titrated to ameliorate distress but not to remove the respiratory drive. Some children will require extraordinary doses to relieve distress, which may result in death. In these circumstances, the legal doctrine of double effect is has been applied. This states that where sedation is used primarily to relieve suffering, it is acknowledged that it may also hasten death as an unintentional consequence and therefore is not illegal in the UK. Separate consideration must be made for paralysing agents, which may have been instituted to optimize active treatment, for example to facilitate high-pressure ventilation. If such agents were commenced before the decision to withdraw support, it may be appropriate to continue them (Inwald and Vandyck, 2001). However, they should not be started after reaching the decision to withdraw treatment, as they would undoubtedly hasten death without relieving suffering. Involvement of palliative care specialists at this stage can be invaluable.

Within paediatrics, it is common for treatment to be withdrawn so that the child may die in his/her parents' arms. Some health-care teams will request that a child is moved to a paediatric intensive care unit for withdrawal of treatment, as the process will be more controlled and peaceful in that environment. Where the outcome is still uncertain, transfer is wholly appropriate.

Inevitably, a child's death will have a devastating impact on his/her family. If possible, the family should be offered specific psychological support during the child's admission and then be offered an appointment approximately 6 weeks later to talk about the child's death and to answer any questions. The authors' experience is that some families will decline the offer. However, a number of families will require multiple appointments. Close communication between hospital teams and the family's GP will facilitate ongoing support. Similarly, health-care teams will deal with a number of deaths and may benefit from opportunities to debrief.

Conclusions

The withdrawal of treatment in children is an increasing occurrence in critical care medicine. Management of such cases requires a multiprofessional team approach and careful deliberation of the associated ethical, legal and practical issues. In addition, the child's parents will be a major influence in the process and health-care teams should consider their views and endeavour to reach an agreement on end-of-life care. Where this cannot be achieved, external agencies, including the legal system, may have to be consulted. **BJHM**

Conflict of interest: none.

KEY POINTS

- A significant proportion of childhood deaths follow withdrawal of treatment.
- Families have a significant role in decision making.
- The decision to withdraw treatment involves careful consideration of ethics, legal and practical issues.
- The Royal College of Paediatrics and Child Health have drawn up guidelines for the withdrawal or withholding of life-saving treatment.

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