ABSTRACT. Increased medical knowledge and technology have led to the survival of many children who previously would have died of a variety of conditions. As these children with continuing life-threatening problems reach school age, families, professionals, and paraprofessionals have to deal with the challenges involved in their care. Some children may be at high risk of dying while in school. When families have chosen to limit resuscitative efforts, school officials should understand the medical, emotional, and legal issues involved.

ABBREVIATIONS. AAP, American Academy of Pediatrics; CPR, cardiopulmonary resuscitation; DNR, do not resuscitate; EMS, emergency medical services.

In recent years, legal trends have expanded educational opportunities, including access to adaptive technology and qualified classroom health aides, for children and adults with a wide variety of disabilities or handicaps. The law provides that children have access to education in the least restrictive environment appropriate for their needs. The general thrust of legislation and policy has been to integrate children with disabilities into regular classrooms. Consequently, some children with chronic and terminal conditions are at risk of dying while attending school. The American Academy of Pediatrics (AAP) has previously addressed the ethical and legal issues involved in decisions to either limit or withdraw life-sustaining medical treatment. Parents who, after consultation with their pediatrician and other advisors, decide to forego cardiopulmonary resuscitation (CPR) of their child may want this decision respected by school system personnel. These decisions challenge all persons involved in a situation in which CPR may be given to balance personal beliefs, strong feelings, legal concerns (especially those having to do with liability), educational considerations, and other issues.

RATIONALE
A request for do not resuscitate (DNR) orders from a parent to school system personnel may represent the parent’s and in some cases the child’s wish for the school to recognize the stage of the child’s illness. A DNR order is not synonymous with abandonment of all medical treatment and does not, of itself, rescind the obligations of the health care team to provide quality care, such as suction, oxygen, and pain medications. Rather, it is a dynamic part of the management plan to be reviewed with the family.

CONSIDERATIONS
Decisions to limit potentially lifesaving therapies typically involve considerable emotional turmoil and careful deliberation about the goals of treatment. The parents, their pediatrician and consultants, religious advisors, and the child try to determine what actions would further the best interests of the child. In many cases, the decision-makers weigh the potential harm of intervention against the potential benefit. For some children (for example, those with muscular dystrophy with cardiac involvement), the risk of sudden death attributable to arrhythmia may be considerable, and the likelihood that resuscitation would be successful is small. In such cases, the patient and family members may be especially concerned that resuscitative efforts would cause physical pain and emotional suffering. The experience for the child could be frightening and uncomfortable and provide no anticipated benefit, such as returning a child to a quality of life previously acceptable to the child and/or the family. These children and their families may not wish the experience of treatment in an intensive care unit that would not affect the underlying medical problems.

While competent adults have legislated alternative means to refuse unwanted medical care, including advance directives, the options for children have remained less well defined. Only a few states explicitly authorize emergency medical services (EMS) to apply advance directives to children. Although lacking explicit authorization, existing statutes generally do not prohibit extensions of DNR orders for children to out-of-hospital situations.

In contrast, the school officials may be worried that a DNR order could be misinterpreted by medically untrained staff, resulting in harm to a child, or they may worry that personnel would feel bound not to respond to an easily reversible condition, such as a mucus plug in a child with a tracheostomy. Administrators have concerns about their personnel responding to circumstances not anticipated by a DNR order, such as when a child chokes on food or is injured. Officials are understandably concerned that they and/or the school or school district could be held liable if personnel failed to act in a way that might have prevented an untoward death.
INTEREST OF OTHER STUDENTS

School officials may be rightfully concerned about the effect of a death in school on other students. The parents of healthy children may not want their children exposed to death in a classroom or other school setting.  

CONCLUSION

Adversarial struggles between school personnel and family members contribute little to the well-being of patients at risk of dying. It is the intent of the AAP that its members respond to the changing needs of their patients. It is also important that pediatricians become involved in the process described here. While little case law, literature, or precedent exists, it is important for pediatricians to be in the forefront. All children deserve an education and are not only entitled to be in the classroom as long as it remains in their best interests but are guaranteed that right under Public Law 94-142, Education for All Handicapped Children Act.  

With the increased numbers of children with chronic and terminal diseases still able to attend school, it is important that pediatricians work with families and school personnel to provide guidance and advice that will continue a child’s education and participation for as long as reasonable.

RECOMMENDATIONS

1. The AAP recommends that pediatricians and parents of children at increased risk of dying in school who desire a DNR order meet with school officials—including nursing personnel, teachers, administrators, and EMS personnel, and, when appropriate, the child. Individuals involved ideally will reach an agreement about the goals of in-school medical interventions and the best means to implement those goals. Concerted efforts to accommodate all points of view will help avoid confrontation and possible litigation.

2. Pediatricians need to assist parents and schools to review, as needed when warranted by a change in the child’s condition, but at least every 6 months, plans for in-school care.

3. Pediatricians need to review the plan with the board of education and its legal counsel. Pediatricians and all other parties involved are encouraged to be realistic and flexible and to make room for negotiation and compromise.

4. Pediatricians and their chapter and district members should work with local and state authorities responsible for EMS policies affecting out-of-hospital DNR orders to develop rational procedures and legal understanding about what can be done that respects the rights and interests of dying children.

5. Pediatricians should work with local school systems and parent–teacher organizations to develop age-appropriate educational programs about death and dying.

6. Pediatricians need to be available to assist teachers and parents when students die at school.

REFERENCES

1. Education for All Handicapped Children Act, 20 USC. 1400 et seq
2. Americans with Disabilities Act of 1990, 42 USC. 12101 et seq
Do Not Resuscitate Orders in Schools
Committee on School Health and Committee on Bioethics

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