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Organizational Principles to Guide and Define the Child Health Care System and/or Improve the Health of all Children

Policy Statement—Honoring Do-Not-Attempt-Resuscitation Requests in Schools

COUNCIL ON SCHOOL HEALTH AND COMMITTEE ON BIOETHICS

KEY WORDS
do not attempt resuscitation, individualized health care plan, school nurses

ABBREVIATIONS
CPR—cardiopulmonary resuscitation
DNAR—do not attempt resuscitation
AAP—American Academy of Pediatrics
EMS—emergency medical services
CCC—complex chronic condition
IEP—individualized education plan
IHCP—individualized health care plan

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abstract

Increasingly, children and adolescents with complex chronic conditions are living in the community. Federal legislation and regulations facilitate their participation in school. Some of these children and adolescents and their families may wish to forego life-sustaining medical treatment, including cardiopulmonary resuscitation, because they would be ineffective or because the risks outweigh the benefits. Honoring these requests in the school environment is complex because of the limited availability of school nurses and the frequent lack of supporting state legislation and regulations. Understanding and collaboration on the part of all parties is essential. Pediatricians have an important role in helping school nurses incorporate a specific action plan into the student's individualized health care plan. The action plan should include both communication and comfort-care plans. Pediatricians who work directly with schools can also help implement policies, and professional organizations can advocate for regulations and legislation that enable students and their families to effectuate their preferences. *Pediatrics* 2010;125:1073–1077

INTRODUCTION

In a groundbreaking statement in 1974, the American Heart Association declared that cardiopulmonary resuscitation (CPR) is not indicated for all patients. Cases of terminal, irreversible illness in which death is an expected outcome do not necessarily merit CPR.[1] Do-not-resuscitate (DNR) orders developed out of efforts to identify patients who do not wish to receive CPR. The terminology eventually changed to "do not attempt resuscitation" (DNAR), acknowledging that resuscitation is not always successful. Some contemporary authors have proposed replacing the term "DNAR" with "allow natural death" (AND) to indicate the positive goal. DNAR orders are physician orders, in contrast to patient directives. In 1994, the American Academy of Pediatrics (AAP) issued guidelines on foregoing life-sustaining medical treatment, including CPR, for children and adolescents.[2] The AAP believes it is ethically acceptable to forego CPR when it is unlikely to be effective or when the risks outweigh the benefits, including the parents' and child's assessment of the child's quality of life.

DNAR orders are not orders to "do nothing," nor do they represent a decrease in the quality or intensity of care. DNAR orders should be implemented in the context of palliative care, including plans for managing pain and other symptoms, as well as addressing emotional and spiritual needs. Components may include disease-directed treatment

but should always include anticipatory and aggressive symptom control. Spiritual, psychological, and social needs are addressed through delineation of the preferred site for dying, the desired conditions of care, who will provide such care, and even who may be in attendance.[3,4]

Although DNAR orders have become accepted within inpatient health care facilities, such as hospitals and nursing homes, there have been challenges to coordinating end-of-life care in other settings, particularly in situations in which the use of CPR is an established standard of care, such as for emergency medical services (EMS). In the late 1980s, states developed mechanisms, such as bracelets and standardized order forms, to alert EMS personnel to patients who did not wish to receive CPR.[5] These mechanisms have various names including prehospital, out-of-hospital, portable, or durable DNAR policies. A task force in Oregon, for example, developed an order form that they referred to as "physician orders for life-sustaining treatment," which specified patients' preferences regarding 4 separate types of medical treatment: antibiotics, nutrition, hydration, and CPR.[6] To encourage compliance, policies may provide immunity from criminal and civil liability and disciplinary action to particular categories of individuals if they act in good faith. Although common, such laws and regulations are not universal and frequently do not apply to children and teenagers.[7]

Increasingly, children and adolescents with life-limiting conditions are living in the community and attending school. Some may wish to forego CPR. It is estimated that on any given day, 2500 adolescents and 1400 preadolescent children are within 6 months of dying from a complex chronic condition (CCC). Although in the United States, deaths attributable to CCCs have decreased over time across all pediatric age groups, those who are dying from a CCC are increasingly likely to do so away from a medical facility. In Washington State, the percentage of older children and young adults with a CCC who died at home increased from 21% in 1980 to 43% in 1998.[8] Concern about the potential ineffectiveness of CPR applied out-of-hospital is justified. The authors of a recent review summarized representative studies by stating that "[s]urvival to hospital discharge typically occurs for $<$10% of these children, and many have severe neurologic sequelae."[9] Some individuals with a CCC and their families may, therefore, wish to forego CPR.

HONORING DNAR REQUESTS IN THE SCHOOL SETTING

Recent health care and societal trends have made it possible for children with CCCs to attend school, which in turn has raised the issue of accommodating students' and families' preferences regarding health care in this context. The Individuals with Disabilities Education Act of 1997 (IDEA) and section 504 of the Rehabilitation Act of 1973 ensured that children with health care needs will be accommodated in school. As a result, more students with CCCs have been able to attend school, despite inherent medical risks and requirements that accompany them. Attending school may be particularly important for children and adolescents with life-limiting conditions. For example, it may permit them to accomplish crucial developmental tasks such as socializing with their peer group. In 2000, the AAP issued a statement advocating that pediatricians assist parents who desire a DNAR order to develop a consensual agreement with school officials about goals and procedures for in-school medical treatment.[10]

Although the law mandates that the school district accommodate students with CCCs by providing supplementary aid and health care services, fulfilling the spirit of the law under all circumstances can prove challenging. The Individuals with Disabilities Education regulations exempt schools from providing "medical services" while stipulating that the provision of intermittent care necessary for the student's participation cannot be used as grounds for exclusion. To fully integrate students with educational, health, or mental health challenges, schools use an individualized education plan (IEP) and/or a 504 plan. These plans, developed collaboratively by the student, family, and school district, articulate the services to be provided to accommodate the child. Within this process, health care needs can be addressed by an individualized health care plan (IHCP), which also may include an emergency care plan. These plans represent an important framework for extending health care into the school environment, because they are integrated with the student's educational IEP or 504 plan. The essential role of the licensed school nurse in the development and implementation of a student's IHCP is supported by the AAP.[11] The IHCP is a crucial factor for the participation of children and adolescents with CCCs in school, and it offers them the opportunity to remain in school.[12]

Although DNAR requests in schools are becoming more accepted, a minority of school districts have adopted policies on this topic. The percentage of schools in which health services staff were reported to follow DNAR orders increased from 29.7% in 2000 to 46.2% in 2006 according to a Centers for Disease Control and Prevention survey.[13] Another study revealed that 80% of the nation's 50 largest school districts and districts in 31 additional state capitals did not have a policy, regulation, or

protocol supporting a student's DNAR order in 2005.[7] For a DNAR order to be applied within the school setting requires more than just the cooperation of the school district. Without an overarching local or state regulatory or legal framework, honoring the request and not performing CPR potentially represents a liability for the staff members who honor them.

After the AAP policy statement on DNAR orders in schools was published in 2000, articles and commentaries from physicians, lawyers, school nurses, and school administrators raised several concerns.[14,15] Some argued that schools are not medical facilities. Without education, their staff members have a limited understanding of a child's medical condition, care requirements, or expected course. In a cardiac or respiratory arrest situation, school staff members lack the training and perspective regarding when to effectuate a DNAR request. Faced with developing symptoms that may culminate in cardiac or respiratory arrest in a child, they may be uncertain how to proceed. A student's arrest may not be the result of the underlying disease process but rather caused by another, reversible cause. Some individuals also may voice an unwillingness to "stand around and do nothing" for legal or moral reasons. In addition, an arrest is a startling event to witness and potentially traumatic for bystanders when CPR is withheld.

It is important for the pediatrician to understand, acknowledge, and address these concerns openly and sympathetically. The DNAR order directs laypeople trained in CPR to forego using their resuscitation skills in the case of an arrest, irrespective of its etiology. The student's IHCP should direct the staff to provide specified comfort-care measures such as holding him or her, providing supplemental oxygen, or keeping the student warm. Notification of the school nurse and/or activation of EMS may both provide staff much-needed support and the student a broader range of interventions, if warranted. Parents and adolescents need to acknowledge these realities as part of their permission and assent. Pediatricians and school nurses should collaborate to develop plans that can be successfully implemented in the school environment.

Several commentators have expressed concern regarding the effect of withholding CPR on the other students. The implementation of DNAR requests in schools is not, however, the only situation that may engender distress for bystanders. Witnessing unsuccessful CPR may also be traumatic.[16] Action plans should specify a location to which staff can move the student in case of an arrest. In addition, many schools have developed counseling resources for a wide variety of potentially traumatic events.

The legal context in which such planning occurs is complex, and pediatricians and school staff members who honor a DNAR request may not be explicitly protected by the law.[7,14] (Similar issues related to EMS personnel are beyond the scope of this statement.) The ability to honor DNAR requests in schools may be influenced by a variety of factors including state statutes or regulation, judicial decisions, state attorney general's or local prosecutor's actions, and local school district policy or procedures. Although most states permit physicians to write out-of-hospital DNAR orders, few states provide legal authority for advance health care directives by minors. Even fewer states provide explicit legal protection against liability for school personnel who honor a student's DNAR request. Because of the complexity and fluidity of state laws and regulations, pediatricians should contact the AAP Division of State Government Affairs for current information. They should also contact local school districts for information about related policies and procedures.

Pediatricians, therefore, need to respect the school staff's concerns when approaching them on behalf of a family who desires to forego CPR. Still, as results of a study by Kimberly et al[7] illustrated, 1 of 5 school districts that reported having a DNAR policy are in states that do not offer explicit legal indemnification, a finding corroborated by the School Health Policies and Programs Study of the Centers for Disease Control and Prevention.[13] Creating a legal framework in which schools and their personnel are immune from liability when complying with a DNAR request in good faith is a crucial step toward furthering acceptance of DNAR requests in schools.

Even when medical justification and legal indemnification exist at the local and state levels, the schools still need support in adopting policies on DNAR orders. The pediatrician's best ally when approaching the school staff is the school nurse. Although school nurses typically are the health authorities within schools, staffing restrictions may limit their availability during an arrest. Thus, individuals without formal clinical training may be the first personnel at the scene and, therefore, need guidance. To ensure the effectiveness of the DNAR plan within the child's IHCP, the pediatrician may need to help school and local EMS staff to understand its implementation.[17] One means of promoting an informed and prepared population for the circumstances surrounding a DNAR order is to incorporate teaching about DNAR orders within training on CPR.

THE PEDIATRICIAN'S ROLES

Pediatricians and their professional organizations have a variety of potential roles in supporting patients and

their families in their efforts to achieve school integration, especially in the face of life-limiting conditions. Primary care providers and subspecialists who serve as a medical home frequently participate in the development of IEP and/or 504 plans. When appropriate, they can help the school nurse to integrate a DNAR request into the student's IHCP. The pediatrician can assist the family to educate the relevant parties about the child or adolescent's condition, potential complications, and health care goals. It is crucial that physicians be open and sympathetic when listening to the concerns of others about dealing with a potential arrest situation. The most effective tool a physician can offer school staff members is a specific action plan (see Table 1). Presentation of the order to the EMS team, along with the child's use of a medical identification bracelet indicating the DNAR status, will ensure recognition of the child's and family's wishes for end-of-life care. In the unusual event that a student with a standing DNAR order does experience cardiac or respiratory arrest at school, the communication plan and physician's clearly written comfort-care plan will be critical for directing staff actions in lieu of starting CPR. The AAP supports adequate physician reimbursement for these important services,[18] which may be reported as part of the care plan oversight codes (*Current Procedural Terminology*[19] [CPT] codes 99339–99340).

Pediatricians who work directly with schools as school physicians or consultants can help school nurses, administrators and staff, the school board, the district's legal counsel, and EMS personnel understand these issues and participate in developing appropriate school policies (see Table 2). Pediatricians who create CPR-training resources should consider including information regarding requests to withhold interventions. Pediatricians and their professional organizations can assist these efforts by advocating for regulations and laws to support families and their children's wishes by protecting all individuals who act in accord with a DNAR request.

TABLE 1 Components of a DNAR Order

The DNAR order within the IHCP should outline the child's needs and provide specific directives for the staff to follow in the event of a cardiac or respiratory arrest. The elements of the plan should include:
Identification of staff members who should be informed of and educated about the IHCP and the DNAR order
The location to which the child will be moved if serious distress or sudden death should occur at school or plans to remove onlookers from the area if the child cannot be moved
Which comfort measures should be offered to the child
Protocols for notification of the prearranged EMS provider
Protocols for notification of the family and primary care physician
Protocols that define steps to take should the child die in school
Designation of the clinician who will pronounce the child's death (physician, nurse practitioner, or physician assistant)
A specific plan for removing the body from the school to a local health care facility or designated funeral home, including such details as the type of vehicle to be used, where it will park at the school, who will clear the corridors, and what kind of transport equipment will be required to move the body to the waiting vehicle

TABLE 2 Factors Shared by School Districts That Honor DNAR Orders

Presence of a district policy on the approach to the child with a DNAR order
Special consideration to meeting the needs both of the child and family and the other students and staff
A process for ensuring privacy during the event, such that students and staff other than those designated in the IHCP are removed from the scene
Involvement of the child's primary care clinician, the district's legal counselor, and the local EMS provider to reach an agreement on the care that EMS is able to provide
Reconciliation of all state statutes, including those on pronouncement, involvement of the medical examiner, and the procedure for limiting EMS actions at the scene
A process for conveying the plan to the school's staff with the assistance of the school nurse
Postevent planning for assisting the school's community to deal with the death of a student

RECOMMENDATIONS

1. Whether in a medical facility or in the community, the family of a child or adolescent with a CCC should be able to direct their caregivers to withhold CPR when its application is unlikely to be effective or when the risks outweigh the benefits.
2. Pediatricians should work with school nurses to incorporate the student's and family's preferences within the student's IHCP, including not only the decision to forego CPR but also a clearly written, specific approach for providing him or her comfort care. Physicians should receive adequate reimbursement for providing these important services.
3. Pediatricians, particularly those contracted by school districts, can support patients and their families by encouraging school administrators and staff members to implement a policy that accommodates health care preferences, including DNAR orders, at the school-district and school-building levels.
4. Organizations that develop training materials on CPR are encouraged to include information about the possible outcomes of CPR and about the option of withholding resuscitation as part of their curriculum.
5. For decisions to forego CPR to be respected outside the hospital environment, pediatricians, pediatric medical subspecialists and surgical specialists, AAP chapters, and

local leaders will need to advocate for regulations and laws that respect the rights of families and, when appropriate, children and adolescents to direct end-of-life care. Such laws should protect the school, school staff members, and EMS staff members who act in accordance with a decision by the family of a student with a CCC to forego CPR.

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