

Pediatric Do-Not-Attempt-Resuscitation Orders and Public Schools: A National Assessment of Policies and Laws

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Some children living with life-shortening medical conditions may wish to attend school without the threat of having resuscitation attempted in the event of cardiopulmonary arrest on the school premises. Despite recent attention to in-school do-not-attempt-resuscitation (DNAR) orders, no assessment of state laws or school policies has yet been made. We therefore sought to survey a national sample of prominent school districts and situate their policies in the context of relevant state laws. Most (80%) school districts sampled did not have policies, regulations, or protocols for dealing with student DNARs. A similar majority (76%) either would not honor student DNARs or were uncertain about whether they could. Frequent contradictions between school policies and state laws also exist. Consequently, children living with life-shortening conditions who have DNARs may not have these orders honored if cardiopulmonary arrest were to occur on school premises. Coordinated efforts are needed to harmonize school district, state, and federal approaches in order to support children and families' right to have important medical decisions honored.

INTRODUCTION

Children living with life-shortening conditions can reach a phase in the progression of their illnesses when efforts at resuscitation in the event of cardiopulmonary arrest would no longer be in their best interest. Hospitals and other health care settings have established policies for deciding upon and implementing pediatric do-not-attempt-resuscitation orders (DNARs), including protocols that allow some means of resuscitation to be used (such as oxygen or bag-mask ventilation) while refraining from using more extreme means (such as chest compressions or cardiac defibrillation). Increasingly, however, children and adolescents with terminal complex chronic conditions are dying outside of hospitals (Feudtner, Silveira, and Christakis 2002), a trend that necessitates thoughtful policies regarding how to respond appropriately to out-of-hospital cardiopulmonary arrests. In partic-

ular, school policies pertaining to DNARs warrant careful attention given that children living with life-shortening conditions are legally entitled to attend school in the least restrictive educational environment.

Although the American Academy of Pediatrics (2000), the National Association of School Nurses (2000), and the American Heart Association (Hazinski et al. 2004) have each recently addressed student DNARs, no nationwide assessment of school DNAR policies exists. Believing that such information would better inform decision-making regarding the formulation or revision of these policies, we surveyed public school district policies in the 50 largest US cities and all US state capital cities, and situated these local policies in the context of ethical and quality-assurance considerations, and pertinent state and federal legislation.

Keywords

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METHODS

We selected the 50 largest cities in America according to the 2000 US Census and supplemented this initial sample frame with those 31 state capitals that were not among the largest cities in America. We selected this sample frame because we believed that the school systems in these aggregate 81 cities would represent (a) those systems responsible for many children and thus those with widely applied DNAR policies and (b) those systems most likely to keep abreast of state laws as they pertain to public schools.

We gathered data from the 81 school systems by first investigating the school district web sites. Some systems posted their school board policies and regulations on the World Wide Web; when policies dealing with student DNARs were available among these online policies, we relied on this data source. Most often, however, we had to place telephone calls to the boards of education or superintendents' offices, using contact information listed on the web. These resources usually provided us with the requisite information; when they could not, they forwarded us to legal council or health personnel who answered our questions.

Policies were then classified according to (a) whether there was an official written school district policy, rule, or procedure for student DNARs, and (b) whether school personnel reported being able and willing to honor student DNARs in at least some cases, based either on the written policy or on standard practice in the absence of a policy.

Of the 81 public school systems from which we sought data during January and February of 2004, 80 (99%) responded with information about the presence of a district policy regarding in-school student DNARs. Of those 80 districts that did offer this initial information, 70 (88%) were able to definitively answer whether they would be able to honor a student DNAR if presented with one irrespective of having a district policy.

In order to set these school policies in their pertinent legal contexts, we compiled relevant state laws from all 50 states and the District of Columbia on out-of-hospital DNARs, advance directives, living wills, and the provision of health care in public schools. Each law was classified on the basis of its applicability to minors and its legal protection of persons who honor health care decisions in schools. Since some laws were ambiguous and required interpretation, the laws were classified independently by two individuals. After cross-

validation of results and further review, we were still unable to confidently classify the legal standards in 6 states: California, South Carolina, and Vermont were ambiguous about their applicability to minors; Georgia, Mississippi, and New Hampshire were unclear regarding legal protection of people other than medical professionals who honor DNARs. In our analysis, we classified CA, SC, and VT laws as not applying out-of-hospital DNARs to minors, and GA, MS, and NH laws as not protecting people who honor DNARs other than medical professionals.

RESULTS

Among the 80 responding public school districts, 16 (20%) reported having a policy, rule, or procedure explicitly regarding the honoring of student DNARs (Table 1). Among those 16 districts with policies, 10 (63%) prohibit the honoring of student DNARs by school personnel, while the remaining 6 (Boston MA, Cheyenne WY, Grand Rapids MI, Jefferson County KY, Palm Beach County FL, and Washington DC) allow school personnel to honor them.

Although the remaining 64 school districts (80%) have no policies that refer explicitly to DNARs, 13 of the 64 (20%) are still able and willing to honor DNARs given certain circumstances such as a written order from a physician or a court order. 41 of the 64 (64%) stated that they are never able to honor student DNARs, and 10 (16%) were unwilling or unable to confidently state whether or not they could honor such orders. In total, 19 school districts of 80 (24%) reported that they could honor certain student DNARs.

17 states and the District of Columbia (33%) provide statutory authorization of advance health care decisions for minors; the remaining 34 states (67%) allow such decisions only for adults. 43 states and the District of Columbia (86%), either

Table 1. Most School Districts Have no DNAR Policy and Would not Honor a DNAR.

		<i>Would a DNAR be honored?</i>			
<i>Does school district have a policy?</i>	<i>Yes</i>	<i>No</i>	<i>Uncertain</i>	<i>Total</i>	
Yes	6 (8%)	10 (13%)	—	16 (20%)	
No	13 (16%)	41 (52%)	10 (13%)	64 (80%)	
Total	19 (24%)	51 (64%)	10 (13%)	80 (100%)	

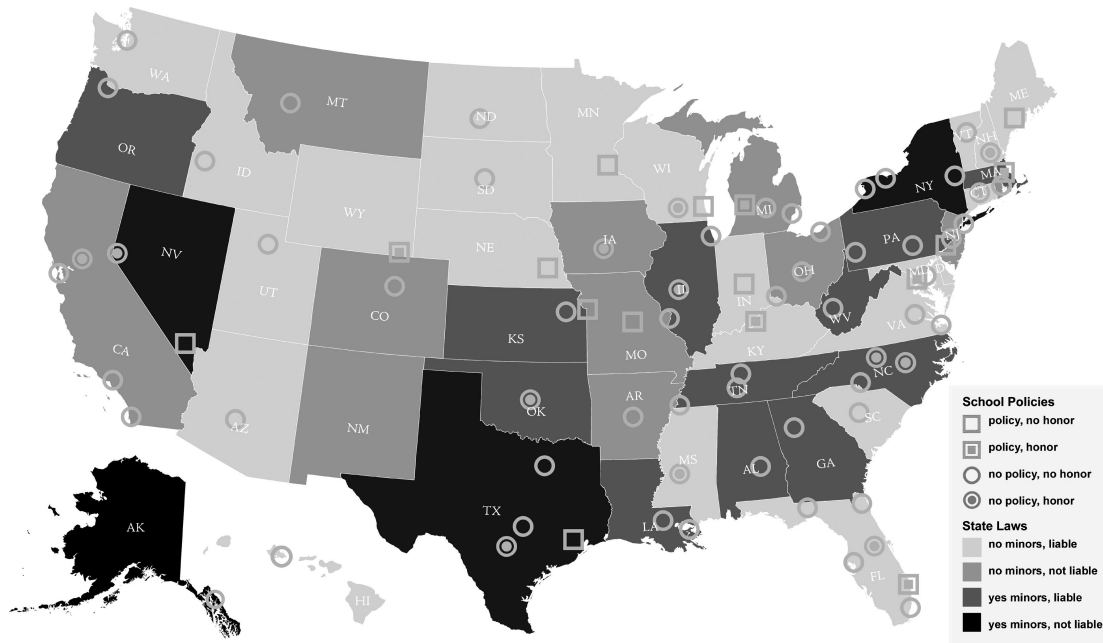


Figure 1. School DNAR policies and state laws are often discordant.

by policies or administrative regulations, permit physicians to write “out-of-hospital” DNARs (Figure 1). These out-of-hospital DNARs are permitted in all 17 states and the District of Columbia that also allow advance health care decisions for minors. Among these 18 permissive jurisdictions, however, only 5 have laws explicitly providing legal protection against criminal or civil liability to school personnel who, by honoring a student’s DNAR, do not attempt resuscitation. Considering all 50 states and the District of Columbia, legal protection for school personnel who honor DNARs exists in 16 states and the District of Columbia (31%). Among the 19 school districts reporting that they would honor student DNARs, 13 reside in states that have no laws to protect school personnel from criminal or civil liability for withholding CPR. Conversely, of the 61 districts reporting they would not honor student DNARs, 18 are located in states where laws do offer such protection.

DISCUSSION

Most school systems in our sample (80%) had not addressed student DNARs in their districts policies or procedures, and a sizable majority (64%) would not honor student DNARs under any condition. Although most states and the District of Columbia now have legalized out-of-hospital DNARs (86%), only 17 of these states allow advance health care de-

isions for minors, and most laws (69%) would not protect school personnel from legal liability were they to comply with student and family wishes not to attempt resuscitation. We also note that potentially problematic discrepancies between school board policies and state laws were common.

These findings regarding school DNAR policies should be generalized cautiously. We sampled a minute fraction of the 14,859 public school districts in the US (U.S. Department of Education 2002). Because our data sample includes some of the largest and most prominent districts, our findings may not be representative of smaller school systems, nor of private or parochial schools. Furthermore, the urban locations of the districts in our sample, combined with their size and potentially diverse constituency, lead us to believe our results overestimate the degree to which all schools have explicitly addressed the issue of student DNARs. These limitations notwithstanding, we believe that our report represents an accurate assessment of public school DNAR policies among those school districts that we sampled.

Given the relative paucity of school DNAR policies found in this nationwide assessment, and the concomitant conflicts with or ambiguity of state laws, school districts and state legislatures may seek to formulate or revise policies and laws pertaining to students with DNARs. Such policy efforts, incorporating ethical, legal, and quality-assurance

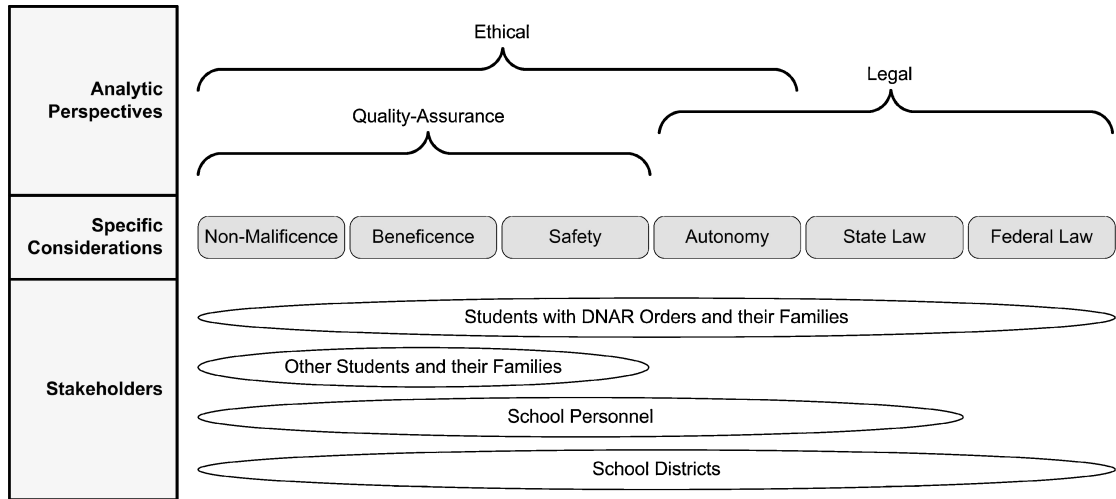


Figure 2. School DNAR policies should accommodate six considerations.

analytic perspectives, may wish to accommodate six specific considerations and how they impact various stakeholders: (1) autonomy, (2) beneficence, (3) non-maleficence, (4) safety, (5) state law, and (6) federal law (Figure 2).

Consideration 1. Autonomy

Given a range of choices among medically appropriate options, competent patients are entitled to make decisions guided by their own values. In the pediatric domain, both ethical consensus and common law (law generated by court opinions rather than by legislative bodies) grant parents medical decision-making autonomy regarding the care of their children. While physicians, school principals, representatives of the state, or others can advise parents regarding what is in the best interests of their children, parents are vested with an independent capacity and authority to make medical decisions. Only in cases of evident maltreatment, recklessness, or neglect should the state intervene (Goldstein et al. 1986; *In re Phillip* 1979). Respect for a child’s nascent autonomy is also important in the pediatric medical context, as evidenced by policies that assert that children should participate in medical decision-making commensurate with their developmental age, and that their assent to treatment should be an important consideration (AAP 1995). Accordingly, children living with life-shortening conditions and their parents have considerable authority to direct the manner of their pediatric end-

of-life health care, including refusing certain treatments that may temporarily forestall an inevitable death.

In a widely cited legal opinion, the Attorney General of Maryland argues that common law establishes the constitutional right of parents to make reasonable health-care decisions on behalf of their children, decisions that may include physician-approved DNARs for certain pediatric patients with terminal illnesses (Curran 1994). Schools generally operate on the principle of *in loco parentis*, the principle that stipulates that when children are in school, school faculty and staff assume the protective duties of parents. When schools know of a DNAR for a student, however, they have no authority to substitute their own judgment regarding treatment in lieu of the documented, parent-authorized DNAR order. Such a substitution represents an unconstitutional encroachment upon the parent-child relationship and parental autonomy to make medical decisions. According to this analysis, school personnel could not be held liable for upholding any reasonable parental decision, even when that decision is a physician-issued DNAR. In fact, quite to the contrary, performing CPR on a student with a DNAR would represent an “unwanted touching” and could therefore be considered physical battery (Curran 1994). Failing to honor a physician-approved and parent-authorized DNAR stating a specific preference to have resuscitation efforts withheld would, in other words, be both an unethical *and* illegal usurpation of autonomy.

Consideration 2. Beneficence

Schools should afford all students the maximal potential for benefit. Although some stakeholders may view the mandatory administration of CPR to any student having a cardiopulmonary arrest as a common-sense way to maximize benefit, such a perspective may not recognize the low likelihood of success for out-of-hospital pediatric CPR (Pitetti, Glustein, and Bhende 2002; Ronco et al. 1995; Schindler et al. 1996), or of the American Medical Association's assertion that "the purpose of CPR is the prevention of sudden, unexpected death. CPR is not indicated in situations where death is not unexpected" (AMA 1980, 453). Since the administration of CPR to a child whose death is impending due to a chronic terminal illness may cause far more harm than good, there is no inherent ethical obligation to provide CPR on the basis of a principle of beneficence.

By contrast, schools that adopt policies enabling DNARs to be honored can directly benefit students with DNARs and their families by promoting individualized advanced care planning. If an adverse medical event were to occur on school premises, such plans could improve the quality care that the child receives by instructing how to best manage symptoms, maximize comfort and peacefulness, and safeguard the child's dignity. Plans can also detail how to quickly contact the parents as well as to summon other designated persons to provide social or spiritual support. Under these arrangements, parents who do not want resuscitation attempted on their children with life-shortening conditions may feel more secure that their parental preferences and prerogatives will be respected, and thus more inclined to have their children attend school.

Even for school systems that prohibit honoring student DNARs, some of these benefits could accrue if they established protocols to provide a child's DNAR to emergency medical services (EMS) personnel or other non-school staff responders, and to contact parents immediately and enable them to intervene in the care that their child receives. Furthermore, all school districts—regardless of their DNAR policies—should make bereavement counseling available for anyone affected by the death of a student, whether or not that death occurred in the context of a DNAR.

Consideration 3. Nonmaleficence

The medical resuscitation procedures inflict injury and potentially physical suffering with the expect-

ation that these harms will be outweighed by subsequently favorable patient outcomes. When such desired outcomes cannot be reasonably expected, then careful consideration of harm assumes primary importance in assessing whether CPR should be performed. In advanced resuscitations, for example, EMS personnel may insert needles, catheters, and tubes; they may initiate chest compressions; or they may administer medications and cardioversion shock. For a terminally-ill child with a DNAR, however, the very slight chance for a positive patient outcome is not likely to compensate for these harms. Rather, a transiently "successful" resuscitation will likely prolong physical and emotional suffering for the child and the family. After EMS transport from the school, such a child may experience a profound escalation of hospital care, an escalation that might ultimately require parents to decide whether to discontinue certain forms of life-sustaining therapy. Avoiding such an emotionally taxing decision is a frequent motivation for authorizing a DNAR in the first place. Once in the hospital, the terminally-ill child would almost certainly die there, which may also be counter to patient or parent wishes as expressed in the DNAR. Although each clinical situation is unique, we hold that the injunction to minimize harm implies a strong duty to withhold CPR for terminally-ill children with DNARs in the school setting.

Potential harms to other members of the school community—students, teachers, school nurses, and other school staff—also need to be considered and minimized. For instance, bystanders to a student with an DNAR having a cardiopulmonary arrest might perceive withholding resuscitative efforts emotionally difficult or ethically improper. Advance planning should include provision of comfort care to avoid the potentially troubling semblance of "doing nothing," and policies should further ensure that counseling is available, as argued above, and that there is means by which to honor the values of staff morally opposed to DNARs.

Consideration 4. Safety

School policies that enable student DNARs to be honored must have in place safeguards to prevent errors. Scrupulous and readily-accessible documentation of which students have DNARs would be essential. All state laws for out-of-hospital DNARs require some form of readily visible identification on their person; such techniques in school would facilitate honoring DNAR while minimizing the

possibility that a student without a DNAR could have CPR inappropriately withheld. Schools that choose to honor student DNARs should also have well-rehearsed chains of command, defined roles, and sufficient training to assure that emergency care, including comfort care, is provided properly. Because school staff personnel without medical training or understanding of a student's complex clinical status may not have the ability to interpret or respond appropriately to serious medical events (Rushton, Will, and Murray 1994; Younger 1992), the orders containing the DNAR should provide clear guidance regarding how to proceed in the event of a medical decompensation or cardiopulmonary arrest. Indeed, a standardized pediatric DNAR form should be developed and tested to assure that individuals responsible for the care of sick children can quickly and accurately discern the intentions of those who issued the orders and conduct the care of the child in a manner consistent with these intentions.

Consideration 5. State Law

In addition to their obligations to students, families, and employees, school districts must consider the laws of their respective states as they apply to "out-of-hospital" or "pre-hospital" DNARs. These laws function by limiting the criminal and civil liability of those who withhold CPR from persons with out-of-hospital DNARs. However, only 43 states and the District of Columbia have out-of-hospital DNAR laws or administrative regulations, and these laws and regulations usually limit liability only for licensed health care providers such as hospice nurses and emergency medical services personnel. In fact, 13 of the 19 school districts that reported that they would honor student DNARs are in states whose laws would not explicitly protect school personnel from civil or criminal liability for homicide or wrongful death if they were to withhold CPR from a student. School administrators and families should therefore seek to influence change of state laws in order to protect non-medical-professionals who honor important end-of-life decisions.

Making matters more complicated, some state laws require schools to honor DNARs, even though many regulations do not allow minor patients to have out-of-hospital DNARs or will not protect anyone other than healthcare providers for honoring them. In New Jersey, for example, school systems

are faced with State Department of Education code requiring them to honor student DNARs (New Jersey Administrative Code 2004) alongside state law that fails to extend legal protection to school personnel who do so (New Jersey Permanent Statutes 2004). School administrators, school personnel, and families of students with DNARs must clearly educate themselves about relevant state laws as all stakeholders attempt to balance the differing legal and ethical risks of each potential DNAR policy.

Consideration 6. Federal Law

School DNAR policies and state laws also reside in the encompassing context of federal law. As recipients of federal money, school systems must comply with the Individuals with Disabilities Education Act of 1997 (IDEA). IDEA was enacted "to ensure that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs" (IDEA 1997). Several authorities, including the Florida State Department of Education, have suggested that IDEA can be interpreted to require school districts to provide "related services" to honor DNARs, which is one form of a "unique need."

In dealing with medically fragile children, schools systems must also give consideration to §504 of the Rehabilitation Act of 1973. Like IDEA, Section 504 requires that "no otherwise qualified individual with a disability in the United States . . . shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance," including "local education agencies" (Rehabilitation Act 1973). Because a school policy prohibiting personnel from honoring student DNARs might be construed as a policy that subjects certain medically fragile children to discrimination, the law could be interpreted to require schools to honor DNARs.

CONCLUSION

Despite the complexity of crafting school DNAR policies, school systems and state governments should address this matter forthrightly. Policies should be guided by the principles of autonomy, beneficence, and nonmaleficence, and take into consideration issues of safety and relevant statutory law. Deliberations regarding school DNAR policies

should acknowledge, but not be dominated by, the nebulous threat of litigation against the schools. The resulting policies and their implementation will have to account for the fact that many school systems operate with insufficient resources to attend to various important matters of child well-being. Finally, the outcome of efforts to improve how children with life-shortening conditions are treated at school might benefit from a national stakeholder conference seeking to delineate the problems that hinder reasonable and just school DNAR policies, and subsequently to formulate integrated strategies to harmonize and coordinate school, state, and federal responses. Only through open and cooperative efforts by all relevant stakeholders can the end-of-life care decisions made by families of children with life-shortening conditions be honored. ■

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COMPETING INTERESTS STATEMENT

The authors declare that they have no competing financial interests.

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