

The ethics of pediatric resuscitation in public schools

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Abstract

Discussions of end-of-life care and policy are often centered on aging populations or adults with terminal illnesses, but rarely do they discuss such issues as school attendance and special education policy. Public school policies regarding the attendance of children with life-shortening illnesses are often ambiguous, and the rights of children with do not attempt resuscitation (DNAR) orders in place are rarely clear. The literature surrounding DNAR policies in public schools is alarmingly sparse. This article discusses these and state policies and argues that DNAR policies are outside of the bounds of school policy. Further, I claim that common assessments of children's rights are insufficient for considering the rights of children with terminal illnesses because of their emphasis on the future.

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Introduction

Ethical issues surrounding death and dying are becoming increasingly relevant as medical technology becomes more sophisticated. The ability to prolong life raises complicated questions, particularly for terminally-ill children, on how to define terminal illness and quality of life; the way in which these concepts are defined will ultimately influence end-of-life care policies and practices. .

Public schools have recently been a focus of pediatric bioethics debates, particularly with the passing of the Individuals with Disabilities Education Act (IDEA), a federal law mandating that all children under the age of eighteen are to be given "a free and appropriate education in the least restrictive environment" [1]. Children who have life-threatening or -shortening illnesses often want to attend school, which is supported by their parents, to maintain some sense of normalcy. Since IDEA was originally intended to ensure that students with physical handicaps, cognitive and developmental disabilities, or autism

spectrum disorders received a free and high-quality education, providing these accommodations for terminally-ill children has proven to be complicated. Still, the law mandates that school districts address questions about how to best care for seriously ill children and public schools' obligations.

One difficult issue to be addressed is having resuscitation procedures and advanced directives for children who are suffering from life-shortening illnesses. A do not attempt resuscitation (DNAR) order is often directed by parents for children who are especially suffering, compelling physicians to withhold any extreme life-saving measures if a child experiences cardiac arrest or a similarly critical complication. DNAR orders are particularly complicated for school-attending, terminally-ill children. Should public schools be compelled to respect and execute DNAR orders under IDEA?

In this paper, I address that question by considering Joel Feinberg's principle of the child's right to an open future [2] with regard to end-of-life healthcare

ethics and comparing it to the aims of IDEA [1]. I then look at the existing DNAR and public school policies in New Jersey and argue that executing pediatric DNAR orders in public schools is outside the scope of IDEA and is potentially harmful to other students and staff given the ambiguous laws and policies and lack of support in most public school systems for such medical decision-making.

End-of-Life in Pediatrics and the Child's Right to an Open Future

IDEA, amended in 2004, protects children with physical and other health impairments by mandating that each state must offer students a learning environment that is minimally restrictive given their special needs [1], consistent with Joel Feinberg's principle of the right to an open future [2,3]; parents have an obligation to keep anticipatory rights in tact by making decisions for their children that are minimally restrictive on their freedom to choose between ways of living. IDEA is essentially an application of Feinberg's principle that specifically involves education.

What becomes of a child's anticipatory rights, however, if the child's life will inevitably be shortened? Do schools still owe that child an educational environment that keeps his or her future rights in tact? And to what extent should these rights be preserved? Our hesitance to address these questions may be due to the tragedy of childhood death and the general reluctance to address pediatric end-of-life issues. While the care of terminally-ill pediatric patients is certainly a rich problem for bioethics, it is not clear that there is an obligation to provide an educational environment that protects for their anticipatory rights.

Feinberg calls these rights anticipatory rights because they should be guarded until the child is capable of self-determination and adult decision-making. Similarly, IDEA designates that accommodations within a child's educational environment should be made in order to increase the likelihood that the child will become self-determining. For children with life-shortening illnesses who will never reach self-determination, education seems more accurately a measure of comfort-care than a mechanism through

which children will become autonomous. Since schools are not equipped or obligated to provide comfort care, and terminally-ill children have no anticipatory autonomy to protect, it seems that schools only have an obligation to prevent harm to any students they enroll.

Despite some differences, there are strong analogies between discussions of the education rights of terminally-ill children and the conception, abortion, or genetic modification of potential children and their future autonomy and right to an open future. Davis [4] maintains that limits should be placed on parental autonomy even relative to potential children. Davis claims that parents should not be able to consult a genetic counselor to help them conceive a child who shares their disability. Feinberg also argues for this: knowingly birthing a child with extreme impairments is a violation of the child's rights.

Markie [5] calls this the problem of nonidentity and argues that people who are not yet conceived or some who are conceived but not yet born have no right to come in to existence. However, if they are brought in to existence through conception then we have a right not to harm them or bring them in to existence to a life not worth living. Markie hypothetically describes a woman who is thinking about conceiving a child but is taking medication that can potentially cause birth defects. When advised against conception by her physician, she conceives a child anyway, before finishing her medication. Markie argues that she has done the fetus no moral harm because at the time of her actions there was no person to harm. Continuing the medication after conception, however, would be acting immorally because a subject of her harm would then exist.

However, what if it is known that the baby will be born with a birth defect and will die shortly after birth? We might argue that the fetus still has a right not to be harmed before birth and that the mother has an obligation to abstain any potentially harmful behaviors. The grounds for the mothers' obligations and fetus' rights would be the existence of something that can be harmed.

Such rights and obligations are limited, however. If the mother knows that the fetus will not survive after birth, it would be irrational, for example, to claim that she has an obligation to research health insurance

policies for the child, take prenatal vitamins, or save money for raising the child. The fetus could not be said to have an anticipated existence in the traditional sense. The fetus's right not to be harmed does not entail an obligation on the mother's part to anticipate its future.

Likewise, schools should be required to not harm terminally-ill students and should offer them the same quality education as their healthy peers and allow them to attend school provided that they are medically able. This right not to be harmed, however, does not require the school to respect anticipatory rights of children whose autonomy cannot be anticipated.

Considering the educational rights of terminally-ill children raises many complex, metaphysical questions such as whether Feinberg's principle is relevant if a child does not have a future which we might leave as open as possible in anticipation of autonomy. The stakes of these metaphysical debates are especially high given the policies and laws regarding out-of-hospital pediatric DNAR orders showing that compelling schools to execute DNAR orders might do more harm than good. In the following section, I will discuss these policies and claim that their potential harm might warrant the rejection of Feinberg's principle as incompatible with educational policy for terminally-ill children.

Pediatric Resuscitation at School: Legally Ambiguous and Morally Troubling Policies

The current policies regarding pediatric resuscitation at school are unclear, perhaps reflective of the debates over children's autonomy and rights. Kimberley et al. [6] conducted a comprehensive overview of state laws and school district policies regarding DNAR execution if an incident occurred while students were on school grounds by looking at the school district policies of the 50 largest cities plus 31 state capitals in the U.S. The results showed that there is little uniformity in such policies, and, in some cases, district policies actually conflicted with state laws or even other district policies about the rights of terminally-ill students to have their DNAR orders upheld if they choose to attend school and/or cause for concern about the need for the DNAR to be upheld.

This is a relevant issue to pediatric bioethics, healthcare policy, and public school policy. Pediatric bioethics are particularly complicated because minors are not extended the same rights as adults in making healthcare decisions. Additionally, schools are often not equipped to handle the medical concerns of students when such concerns are generally the prerogative of the healthcare system. Nonetheless, pediatric DNAR policies in the public schools raise many questions about the quality of care and the restrictiveness of environment for minors.

IDEA promises all minors an education in the "least restrictive environment" available to them, but it is not clear how to best implement this policy for terminally-ill children. While these children should be able to attend school if desired, their parents and healthcare providers are likely justified in having concerns over DNAR policies in public schools. If a school will not agree to uphold a DNAR order, or if there are no clear policies, then these parents and healthcare workers have to weigh the benefits of the child's ability to attend school with the potential costs of the school refusing to follow the order or not knowing to follow the order. If a DNAR order is not followed and an emergency medical team is called instead, the child will be faced with unnecessary medical intervention and care that is not likely to increase the overall quality of the child's life, and actually could decrease it. Also, the child's family might consequently face an emotional and practical toll outweighing any benefits gained by school attendance.

Many states have conflicting policies regarding the execution of DNAR orders in the schools [5]. I use the example of New Jersey here because, as Kimberley found, the problematic issues with its DNAR laws and regulations relative to public schools is representative of many states. Kimberley [6] points out that the NJ Permanent Statute that discusses the legality of executing pediatric DNAR orders extends no legal protection to district employees who honor student DNARs [7].

In fact, many district administrators are not aware of state laws and district policies regarding DNAR orders. Students with DNAR orders are often unofficially discouraged from attending school because DNAR policies are difficult to incorporate

into Individualized Education Plans (IEP) given the number of school personnel with whom students are in daily contact and the training and policy memorization required for its professionals.

This example is also used to illustrate an apparent common theme in policies over pediatric resuscitation: a lack of coherence with legal statutes or an absence of policies altogether. A more thorough look at the New Jersey administrative code that calls for the execution of pediatric DNAR orders in the public school shows that the policies regarding the issue are actually more vague and troubling than Kimberley points out [6], and it is unclear if the administrative code mandates that schools enforce and execute pediatric DNAR orders, or if the policy simply directs school administration to review any DNAR orders in place for students attending the school [8].

Each district board of education shall develop and adopt the following written policies, procedures and mechanisms for the provision of health, safety and medical emergency services and ensure staff are informed as appropriate... (3) The review of Do Not Resuscitate (DNR) Orders received from the student's parent or medical home (N.J.A.C 6A:16-2.1.3) [8].

Unfortunately, the terms of this policy are not made much clearer elsewhere. In their published guidelines for out-of-hospital DNAR orders in New Jersey, the Medical Society of New Jersey (MSNJ), the New Jersey chapter of the American College of Emergency Physicians and the New Jersey Comfort Care Coalition do not mention the execution of pediatric DNAR orders in public schools [9]. In fact, the only mention of pediatric DNAR orders is the suggestion that terminally-ill pediatric patients with DNAR orders in place should wear identifying bracelets so that first responders can easily identify them as DNAR.

As such, the guidelines for out-of-DNAR orders are essentially written for first responders and emergency medical service personnel. The DNAR order documentation that patients or their surrogates are expected to provide to those involved in the patient's day-to-day care is as follows: DO NOT RESUSCITATE: All first responders and emergency medical services personnel are authorized to comply

with this out-of-hospital DNR order. This request for no resuscitative attempts in the event of a cardiac and/or respiratory arrest for (Patient's Name) has been ordered by the physician whose signature appears below. This order is in compliance with the patient's surrogate's wishes and it has been determined and documented by the physician below that resuscitation attempts for this patient would be medically inappropriate. It is expected that this DNR order shall be honored by all Emergency Medical Services (EMS) personnel, First Responders, and other healthcare providers who may have contact with this patient during a medical emergency ([9], p. 13).

Moreover, in New Jersey, end-of-life standards regarding CPR and DNR orders are considered standards of cares, but not laws [9], and thus first responders and other medical personnel are not afforded any legal protection for DNAR execution. To the question of whether medical personnel can be sued by family members for executing a DNAR order that is in place, the guidelines answer:

Anybody can sue anyone for anything in our society. However, if a patient has a valid NJ Out-of-Hospital DNR order and you administer CPR you also run the risk of being sued for violation of the patient's rights. This is perhaps a greater risk ([9] p. 10)

This puts medical personnel in a legally ambiguous position, because the New Jersey statutes do not afford them legal protection whether they execute DNAR or violate orders. Therefore, first responders are not protected from lawsuits if they follow DNAR orders, even though they are compelled to do so. Following DNAR orders in school settings carries a greater potential risk of lawsuit simply because the orders are carried out in an environment that is not traditionally medical and in the presence of children.

The emphasis on emergency personnel actions in New Jersey statutes and guidelines makes their administrative code even more disconcerting. If a child suffers cardiac or respiratory arrest on school grounds, it is likely that school administrators and district-employed health professionals will be the first to provide emergency care to the child, not first responders or EMS workers. School personnel are required by law to have training in first aid and CPR

and school nurses are required have Automated External Defibrillator (AED) training for defibrillators that are available by mandate in all public schools.

Ideally, the New Jersey administrative code would call for all school nurses to be familiar with student DNAR orders and to serve as immediate care providers if a student with a DNAR order suffered cardiac or respiratory arrest. Under the current policies, however, school nurses are afforded no legal protection if they respond in this way and, furthermore, they are not required to be the first to respond. There are so many exceptions that such a policy seems virtually impossible. For example, there is no reference to substitute school nurses and whether they should be familiar with the medical care requirements outlined in the IEP of each student.

Moreover, the administrative code does not reflect that teachers and professional staff will primarily come in to contact with the student in an emergency situation much sooner than any medical personnel, including the school nurse. While these teachers and support staff would administer CPR and first aid under typical conditions, it seems unrealistic to demand that these professionals, who are likely operating under duress, are responsible for protecting other students in the class and calling emergency personnel, react differently if there is a DNAR order in place. Emergency situations in public schools are not the same as other accommodations required under IDEA, and withholding resuscitation is not a realistic requirement of a least-restrictive environment for students with life-shortening illnesses.

Despite this, the statutes do offer guidance to medical and emergency personnel. However, there is no mention of public schools or school administrators in the out-of-hospital DNAR guidelines and therefore no guidance or legal protection for school districts, administrators, and staff regarding how to consider and execute DNAR orders in the schools.

While the state's administrative code under IDEA compels all school districts to review student DNAR orders as part of the process of determining the "least restrictive environment" for each student, it provides very little idea of how to accomplish this. School districts are not required to offer training in end-of-life issues to school nurses or teaching staff, and in effect, should not put them in the legally vulnerable position

of having to enforce DNAR orders. Forcing schools to execute pediatric DNAR orders might harm teachers, administrators and staff, healthy students, and, in the case of attempted resuscitation, the children with the DNAR. Furthermore, a study by Hone-Warren [10] found that the majority of school administrators believe that while having DNAR policies written into public school regulations would clarify how staff should respond in emergency situations, very few thought that DNR policies should be developed for public schools because school administrators and employees typically lack knowledge about DNAR orders and view the idea of DNAR policies as "too emotional" for public school policy.

Of course, this issue is not entirely clear-cut, and many good arguments can be made in favor of enforcing public schools to honor out-of-hospital DNARs for terminally-ill children. Weise [11] identifies at least three arguments in support of this view that can be found in the responses to Kimberley's study [6]. First, authors argued that honoring DNARs would align with the caregivers' duties to not harm the child [11]. Other authors claimed that ethical concerns extend beyond merely principles. Finally, some nursing and pediatric professional societies are in support of school-employed DNARs recognizing the need for personalized care given the capabilities of the school staff.

Weise supports the idea that DNARs should be honored in public schools on the grounds that we have an obligation to protect vulnerable children [12]. It does not seem to follow, though, that this duty extends to contexts such as in Kimberley's study [6]. Compelling public schools to honor DNAR orders is not a matter of protection for the vulnerable, because such a policy does not protect terminally-ill children from harm [12]. All children might have the right to attend school with reasonable accommodations, but the current disability policy in the public schools does not create an obligation to honor such acute clinical accommodations.

Conclusions

While the child and family should be the focus of the decisions and policies over pediatric DNARs, school districts' ability to comply with such policies, and the potential liability and harm that may result from ambiguous policies and inadequate laws is not rigorously discussed in the literature. Kimberley [6] argues that under IDEA school districts ought to be compelled to comply with pediatric DNAR orders and clarify their policies so that students with these orders can attend school without the fear of resuscitation. It is unclear, however, that schools and educational policy makers have any moral obligation to do so.

Public schools' obligations regarding pediatric DNARs are complicated, because while the medical rights of children are often subject to decisions by parents, physicians, and the government, schools are not often considered to be stakeholders [13]. Accommodating students with severe medical problems and terminal illness is not the intention of IDEA. While these students should not be forbidden from school, their parents and physicians should be accountable for any necessary accommodations and medical care required for them to attend school. Parents are well within their rights to include school attendance as a part of their child's comfort-care plan, but cannot compel the school to implement end-of-life care as a part of their child's educational plan.

Feinberg's concept of anticipatory autonomy offers important considerations in cases where a child's open future is at stake [2,3], but this is absent for terminally-ill children thereby eliminating the right of anticipatory autonomy. Feinberg's concept is more or less an effort to protect a child's right to self-determination, such as choosing religion or sexual preference as an adult, not in influencing educational policy [14]. IDEA, as a policy, has self-determination or autonomy that is derived from very much the same reasoning as Feinberg's principle as an aim. Therefore, IDEA relies on principles and values that cannot be applied unless there are any rights or autonomy to be anticipated, which unfortunately in the case of a terminally-ill child, are non-existent.

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