S.A. was born with cyanotic congenital heart disease. Though her childhood was marked by surgeries and hospitalizations, she attended school when able and participated in after-school softball and Girl Scouts. Over time she suffered progressive heart failure and was deemed unsuitable for heart transplant. She became wheelchair bound and increasingly limited in her activities. When she turned fifteen, S.A. and her family asked that she not be resuscitated if she were to suffer a cardiac arrest. S.A. felt there was no point to being resuscitated to die in the near future of her heart disease. Her physicians agreed with her choice, but when the local public school system was asked to honor this do-not-resuscitate (DNR) request they refused. In their rebuttal, officials expressed concern about the impact on other students if she were not resuscitated.

Currently, nearly four thousand children and adolescents in the United States are believed to be within 6 months of dying from a chronic medical condition. Biomedical advances have prolonged survival of patients with complex diseases such as mitochondrial disorders, cystic fibrosis, muscular dystrophy and HIV/AIDS. These children are more likely to live in the community than in the past—for example, in Washington State, the percentage of children with a serious illness who died at home increased from 21% in 1980 to 43% in 1998. Under the 1997 Individuals with Disabilities Education Act (IDEA), which grants the right to education and reasonable medical accommodation for all children, a greater number of chronically ill children also attend school. In 2009, 10–15% of children enrolled in public schools had ongoing health problems and 1–2% had life-shortening conditions including end-stage heart, liver, or kidney disease, cancer, and progressive neurological disorders. School attendance may be particularly important for these children, allowing them to socialize with their peer group, practice life skills, and maintain a sense of normalcy.

It follows that some “medically fragile” school children may have DNR orders in light of their prognosis. DNR orders identify patients who do not wish to receive cardiopulmonary resuscitation (CPR), often in cases of terminal illness where the harms of resuscitation outweigh potential benefits. S.A. feared that if she were resuscitated and transferred to a medical facility, she could be irreversibly intubated or separated from her parents, leading to a painful, lonely, prolonged death. CPR is the only medical intervention that must be performed unless there is an order to the contrary, so DNRs are now relatively standard within health care facilities. In these settings they can be subject to miscommunication and misunderstanding, and in schools they are often contentious and even more challenging to implement. State laws vary from not recognizing DNR orders outside of hospitals at all to requiring extensive paperwork be filed. Even if a school district is willing to implement a DNR, the legal framework to protect staff members who do not try to revive a stricken minor from liability often does not exist. In 2005, a survey in the American Journal of Bioethics found that 80% of the nation's 50 largest school districts did not have a policy supporting student's DNR orders. 76% stated they would not honor student DNRs or were uncertain if they could.
This conflict leaves parents of children with life-shortening illnesses with an impossible choice. As one father articulated: “do I let my child go to school and they might get CPR they don’t want, or we hold them from school and they don’t get the benefits of going.”

**Autonomy to request a DNR order**
The ethical principal of autonomy gives individuals the right to decline resuscitation with an order signed by a physician. In legal cases, performing CPR on a person with a DNR order has been considered “unwanted touching” that constitutes battery. Most states honor DNR orders on minors with life-shortening illness, and in pediatrics, both ethical consensus and common law grant parents the authority to make this decision for their children, with their input. Schools generally operate on the principle of *in loco parentis*, which holds that when children are in school, staff act as parents to promote the interests of the child. It would infringe greatly on parental autonomy and the parent-child relationship for personnel to substitute their own judgment regarding medical treatment. Why, then, are DNR orders not consistently implemented in schools?

Emotional reactions to children with DNRs underlie some of the objections. Officials may wonder why a child whose life is hanging by a fragile thread is in school in the first place. Parents often want their child to lead as normal a life as possible, but school committee members have responded that the school setting is “no place for a dying child.” Alternatively, a child with a serious diagnosis like pulmonary hypertension may appear completely well but be at constant risk of death from a cardiac arrhythmia. This apparent contradiction is unsettling to many faculty and staff.

There are also practical considerations that make implementing DNR orders in school difficult. First, DNR orders are applicable when patients experience cardiac arrest secondary to their chronic condition but may not apply for reversible causes that present with similar symptoms, such as choking. With school nurses often in short supply, personnel who are not medically trained may mistakenly intervene or fail to intervene where they should. Only about 20% of states have legal protection from liability for this kind of error, so it is not surprising that school districts are hesitant to implement DNR orders.

Schools are also often concerned with limiting harm to staff and other students, as their moral obligation to 'do no harm' extends beyond the child with the life-shortening condition. A child dying in school is a burden on staff and students who witness it. A death may be associated with seizures, bleeding, incontinence, or physical struggling that can stretch for minutes or hours. During the process many patients demonstrate signs of pain or emotional distress such as labored breathing or cries for help. Children who witness a student in need may view a failure to apply CPR as abandonment. Furthermore, standard Emergency Medical Service policy is full-response only in many states, so schools may not be able to activate 911 if they wish to honor a DNR order, which limits their ability to provide comfort care measures. After death on site, often a coroner or funeral director must remove the body, which can lead to a long period of disruption and distress.

The issue of DNR orders in schools is more morally ambiguous than it may initially appear. Autonomy grants parents the right to make medical decisions for their child, but parents
necessarily forfeit some of that autonomy when they decide to send their children to school. Both beneficence and non-maleficence seem to obligate schools to honor DNR orders, which are implemented when there is virtually no chance of good resulting from resuscitation efforts. However, schools also have an obligation to “do no harm” to other students, and the school setting may limit their ability to provide the “good” of comfort care to a dying child. Law arising from the ethical principle of justice clearly states that disabled children are entitled to attend school. Furthermore, a terminally ill teacher would not be barred from coming to work if he or she was able to do so, so why should a child have to risk unwanted treatment versus staying at home, bored and lonely? On the other hand, implementing a policy to address student DNR orders may be a resource-intensive proposition, especially for understaffed schools, challenging the principle of distributive justice on a community level.

Towards a solution
A child and family dealing with chronic and severe illness ought to be supported by their community. If the child wishes to attend school, he or she should be able to without compromising medical treatment or wishes about the nature of their death. However, DNR orders in school must be implemented with more care and caution than in other settings to balance good and harm. Families of chronically ill children must be willing to accept this balance.

In the case of an apparent arrest, resuscitation should be withheld if observable symptoms are unmistakably due to the underlying condition for which the DNR was written. However, if there are doubts about the cause, CPR should be initiated, and local laws should be enacted to protect school employees from liability if they follow these requirements. DNRs in schools should be simple and specific – for example, "do not perform chest compressions, do not use a defibrillator, but you may open the airway if he is having difficulty breathing." School districts should also attempt to train a sub-group of teachers in how to respond to medical emergencies, specifically DNRs on file, for when the school nurse cannot be readily available. The school should also have a plan to respond to a death on-site, which can be a learning opportunity for other students to understand what has happened and how to deal with death.

Like most bioethical dilemmas, the issue of DNRs in school requires balancing benefits and harms in a practical manner. When the above requirements are met, the good to the sick child and her classmates is optimized. Unfortunately, S.A. died before she was able to attend school with her sophomore-year classmates, but her case serves to remind us there is a more compassionate way to treat chronically ill school children.

Sources:
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Essay by Kristina Krohn, M.D.
Silence Hurts

Dr. Smith quickly introduced me to Casey, her words running together. “I see you’re here for a colposcopy. Dr. Krohn is a physician working with me today. You don’t mind? Good. Then let’s get started, just slide forward here…”

I positioned myself at Casey’s head, trying to make eye contact. In the past, women usually smile at me.

Casey did not.

Instead, Casey turned away. When she glanced up, her eyes were moist. I tried to think of what I could say. “Are you ok? Why are you crying?” Anything! But my mind went blank. I tried to move near her, to offer words of comfort, to gently touch her arm. I tried small talk, but I did not point blank ask, “Why do you look like you want to cry?”

I stared at Dr. Smith to see if she knew some history, something that would explain Casey’s reaction. But Dr. Smith was intent on studying the cervix. I was struck by the tension in Casey’s legs. Every muscle fiber tensed and quivered, even down to her sock-covered toes, which pointed rigidly up out of the footrests. I was horrified. Time stretched out. My tongue froze. All I could do was turn back and forth between Casey’s face and Dr. Smith’s head between Casey’s legs. I do not think Dr. Smith ever looked Casey in the eye.

Just as Dr. Smith appeared to wrap up the exam, she said, “A lesion.”

At that revelation, Casey seemed to disappear into the exam table. Her blond hair fell over her eyes as she blinked and scrutinized the ceiling.

“Casey. You have two options. I can take care of this now or you can come back for another visit.”

Casey swallowed. Silent.

Dr. Smith continued. “This has been a long exam already and the machine will take ten minutes. If you have a meeting and can’t take that time, I understand.”

“I have to work” Casey squeaked.
Finally, Dr. Smith removed the speculum.

Casey blinked her damp eyes, swallowed and scooted back on the table. She appeared to regain her confidence as Dr. Smith and I walked out of the room.

"Do you have any questions?" Dr. Smith asked me.

I knew she meant medical questions, but the only question I could think of was, “Did you see the fear in her eyes?” I wanted to know more about Casey’s story. Why was the exam so painful for her? Was there something we could have done to support her emotionally?

When I did not respond, Dr. Smith smiled and said, “Interesting case.”

For the rest of the day I noticed how much Dr. Smith did without telling her patients. She seemed to have supreme confidence. The rest of her patients appeared completely at ease with her. They had long-standing relationships and appreciated her methodical, medical manner. They shared stories of how she had saved their lives, their breasts, and their ability to have children. They told me how they will miss her when she retires next year.

All evening I pictured Casey’s eyes: her tense legs, the way she clenched her arms, and the nervous way she played with her fingers. In my head I reviewed the questions I didn't ask, haunted by what I had seen and the thought that I had been a willing accomplice to her pain. I thought of the many bad things in the world and how complacent I am about them. I had always hoped that, when I found myself in a situation where I felt someone was being taken advantage of, I would step forward, I would speak.

I tried to justify what had happened. I reminded myself of the facts. Casey consented to the medical exam: nothing was forced. Weeks later, when I finally had the courage to ask Dr. Smith about it, she was dismissive. “Women are always afraid that I’m going to find cancer or something when I do a colposcopy. The best thing I can do is be thorough. That way if I don’t find anything they know they are okay.” But when I thought of Casey’s face, the muscles flexing in her legs, I worried that the exam was far more traumatizing than Dr. Smith believed. I convinced Dr. Smith to check if Casey had followed up at all. She had not. The day that I met Casey was the last time she came to clinic.

I can make excuses for why I stood there and said nothing. It was my first day with Dr. Smith. I did not know Casey’s story. And so on, and so on.
But I should not have to make excuses.

The morning before Casey suffered through her pelvic exam, I participated in a session specifically designed to prevent medical practitioners from unintentionally emotionally violating young women during pelvic exams. Practitioners use many techniques to give young women and adolescents control, and to make the exam as benign as possible. The main point of the session was that all women should be entitled to control and comfort during a pelvic exam. I returned to the fact that Casey was not given that opportunity. Her fear should have been recognized. She was in a vulnerable position in a doctor’s office and was maltreated. I feel angry that I was part of that situation.

As a medical student and as a resident I had watched multiple physicians in many different settings. As a trainee there are times when I am supposed to do things and be supervised. There are other times where I am not qualified, and instead am supposed to watch and learn from the expert.

But what do you do when the expert does something contrary to what you have learned? What do you do when the expert does something that you find morally wrong? If I saw a physician steal narcotics or sexually abuse a patient, I hope that I would confront that physician or take action. But much more challenging are the times when things are morally gray. Perhaps Dr. Smith knew things I did not know. Perhaps I missed some clue. But somehow I expected more from Dr. Smith. She should have seen the vulnerability Casey felt. I expected more understanding and sensitivity from a female gynecologist.

Despite the reassurances I provide myself, I still contemplate what I did and what I did not do. Slowly, I give myself space to acknowledge my own guilt, and my complacency in Casey’s traumatic encounter.

As I learn to accept my part in Casey’s poor experience, anger at my superiors for allowing this to happen bubbles to the surface. Casey should not have been put in that situation; and I should not have been forced to be a part of it. As a resident it is the job of my program and my superiors to teach me what is right in medicine, not cause me to watch what is wrong. Eventually, I got the nerve to talk with the rotation director. She was as appalled as I was at Casey’s treatment. Not only has the rotation been restructured, but the director is also working to teach residents how to advocate for our patients, even in situations where we are uncomfortable. We should always feel empowered to speak up for our patients.

As physicians, we have always modified “first do no harm.” I understand the need to hurt someone to heal them. People need biopsies, surgeries, and vaccinations. I am also at peace with the need to cause emotional pain, telling someone they have cancer or encouraging them to experience fear in order to overcome phobias. But Casey experienced more pain than was necessary and may not get further treatment because of the trauma she endured. Pelvic exams in young women are an easy example of a medical procedure that can be of great value, but, if rushed, can be truly traumatizing.
If someone is going to do a pelvic exam, expert or trainee, the first step should always be to look the patient in the eye and try to ensure her comfort as much as possible. As pediatricians we undergo special training to work with adolescent girls and create a safe space for them to receive health care, including pelvic exams. With new recommendations to increase the age of initiating pelvic exams many pediatricians will lose this skill. It is important that we stand up for our patients, even when they are no longer our patients but true adults seeing adult providers. As physicians, and pediatricians in particular, we need to ensure that our patients, regardless of age, are treated with the respect and sensitivity they deserve.

I, for one, will always make an effort to ensure the emotional comfort of my patients, especially for invasive procedures such as genital exams, and I will ask that you, my colleagues, do the same. And in the end, I will try to forgive myself for previously staying silent.