Bedside Story

Every Death Is Different

FROM A PHYSICIAN AT A MAJOR MEDICAL CENTER

Now I know why so many stories have been written with the theme: "everything changed in one moment." More than 1,000 days have come and gone, and I still remember one Sunday morning and still follow and feel the effects of one decision.

Rachel was a 9-year-old child who had undergone a major craniofacial reconstruction 10 days before I met her. Her mother had been told that her daugher would die before she reached 5 years of age. Rachel was born with medical problems—generalized weakness that led to difficulty swallowing and coughing. She had repeated aspiration pneumonias and slow growth in spite of a gastrostomy for feeding, and she had difficulty with both verbal and motor development. She had been hospitalized many times, usually for respiratory problems; home nursing was used for her entire first year of life. But Rachel was normal intellectually, attended school and was at age-appropriate grade level, and communicated with her peers, teachers, and family. Over the years, Rachel's mother remained determined to support and teach her daughter, in spite of the awful medical prognosis that doctors had felt was accurate.

When Rachel was 9 years old, her mother eventually agreed with the doctors that a major craniofacial procedure should be undertaken to allow her daughter to develop her speech and improve swallowing. The surgeon had performed many, many of these procedures on children with craniofacial anomalies, the anesthesiologists were specialized in care of infants and children, the Pediatric Intensive Care Unit (PICU) routinely cared for critically ill children, in particular, children who had undergone a procedure similar to the one planned for Rachel.

Rachel underwent the surgery with no significant problems. She did have to return to the operating room on the first postoperative day for a minor revision. Over the next few days, several attempts were made to extubate her trachea, but Rachel continued to require mechanical ventilatory support. Five days after the operation, Rachel suffered a cardiopulmonary arrest. Her endotracheal tube had been removed, but she did not sustain adequate spontaneous ventilatory effort, reintubation of her trachea was difficult, and an arrest occurred. Her mother remained at her bedside. Her father had been absent from Rachel's life for a long time.

Five days after her arrest and 10 days after the surgery, I met Rachel. It was clear that her neurologic status was progressively deteriorating as a result of her hypoxic-ischemic injury during the arrest. Any chances for a recovery were described as something that would be "nothing short of a miracle" by the child neurologist. CT and MRI scans documented diffuse injury. She was in a coma. Six days after the arrest, Rachel's mother agreed that a "do not resuscitate" status was appropriate.

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Nine days after the arrest, a decision was made to extubate Rachel's trachea, provide general care, but not reintubate if her cardiorespiratory status deteriorated. Rachel's mother was stoic, crying, but listening to the child neurologist, the pediatrician, and me (the PICU attending). She wanted to talk to her friends, her family. She wanted time to say good-bye.

I had consulted with an ethicist about doing a tracheostomy. I had talked to the rehabilitation specialist who had helped Rachel in the past and who had examined her repeatedly over the years. Everyone was sad to say that there was no hope for a neurologic recovery, seeing what her status was 10 days after a hypoxic-ischemic insult. I was in charge of the PICU. I knew Rachel had received no sedatives or narcotics for at least 5 days and that her renal and hepatic functions were normal, so that her coma was not related in any possible way to "drug effect."

One day after the recommendation for extubation of Rachel's trachea was made, her mother said she was ready to proceed. I pulled Rachel's endotracheal tube. She started to breath normally. Her mother was at her bedside. When I left the PICU several hours later Saturday night, Rachel was breathing on her own; she required suctioning, but was stable. I talked to the PICU Fellow and the pediatric resident. I had no phone calls about Rachel all night.

When I came back to the PICU on Sunday morning, Rachel was gasping about 6 times per minute. Her hands were cold and mottled, her lips were blue, her face was pale, and her respirations were agonal. Her condition was radically different from what it had been 12 hours earlier. It was clear that she would never survive, that she would die soon, in a few hours. Rachel's mother and the nurses were upset by Rachel's struggling, and her mom asked for a "big dose of something to get this over with." The PICU fellow had told Rachel's mother that we had to be careful about "treating pain and suffering" versus "euthanasia." Mom looked at me and said: "give my daughter some dignity." The mother and her friend were at the bedside and were torn apart by how Rachel looked.

I asked the nurse to get some fentanyl and some versed. I really wondered at that moment if Rachel could feel "pain." She had shown no neurologic function above brain stem level for longer than a week. But I wanted to be sure that she wasn't suffering, that she wasn't feeling some discomfort at some level. She appeared to be struggling with each breath, and her mother was distraught and worried that Rachel was uncomfortable. At other times and with other patients, I had used narcotics and sedatives so that a child did not struggle, did not suffer, with every breath. What I had never experienced was that in spite of large doses of fentanyl, morphine, and versed given into a central venous catheter, Rachel continued to gasp. It was awful.

At one point, I said to the nurse that maybe potassium would be the only way out. I did not feel panic, but the gasping was persistent. We all knew that there was no hope at all. So I asked for potassium. The nurse did not resist or ask any question but just left and returned with a syringe full of a clear liquid. I injected the clear liquid into the same catheter I had been using during the prior 45 minutes. Rachel died quickly.

I talked to her mother for a long time about the awfulness of Rachel's dying so young, and about what she and her son would do now. After that, she left. She refused to have an autopsy performed.

I had other patients to take care of, rounds, dictations. I went on with my work. It wasn't that I didn't feel the enormous impact of what I had just

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done. I had faced the dying of infants and children many times. Although I had never used potassium to treat the discomfort of agonal respirations, I didn't think that what I did that Sunday to take care of Rachel and her mother was a terrible decision or all that different from successfully using morphine to treat the same awful symptom. I felt guilt and frustration that I had not known that Rachel had been struggling in the PICU for hours, that she had received many doses of narcotics and sedatives, but that she had continued to gasp. I wished that I had never left her bedside Saturday evening. I did not like to think about Rachel's mother sitting in the PICU in the middle of the night, listening and watching her daughter gasp.

The next day I got paged to the PICU by the nurse who had handed me the potassium the day before at Rachel's bedside. The nurse admitted to me that she had talked to other nurses about the potassium. I came to the PICU and talked to the head nurse for a long time.

After that, an explosion of events occurred. A call to the district attorney started a homicide investigation. A report to the chief of staff and my chairman resulted in my loss of hospital privileges, and a report to the medical board. A hospital committee chaired by an ethicist was put together to review the "case" and to decide what to do with me. I was suspended for 3 months, but that was extended to 6 months, until criminal charges were settled. The story was in the paper and on the radio. My name was never used, but anyone who knew the setting could figure "it" out.

When I remember how I was treated by some of my colleagues, I think of how bizarre things got. One person that I had known for 20 years told a mutual friend that I shouldn't be seen laughing in public. Another said I should not be seen in the hospital cafeteria. On the other hand, some of my colleagues were unbelievably supportive. Mostly, I remember the friends who just spent time with me, letting me cry, talk, and even laugh. I have never felt so scared and so isolated. I kept thinking that as bad as I felt, how did Rachel's mother ever get through that long night in the PICU, scared and alone?

I have never lost contact with the concept of the power of the death of this little girl. I understood and still understand the huge ethical questions involved. I also know that this little girl was going to be dead in a few hours. A lot of people made and continue to make judgments about issues like this one, but have never stood there at a bedside and had to decide how to take some little bit of suffering away. I have read and read and thought and thought.

I asked a lawyer what the legal definition of murder is. He told me that first degree murder is the intentional killing of a human being with malice aforethought, premeditation, and deliberation. Second degree murder is the intentional killing of a human being with malice aforethought, with wanton reckless disregard for human life. Of all the accusations a district attorney could hurl at me, "malice" or "wanton reckless disregard for human life" did not have anything to do with that Sunday morning. Nothing even close.

This was an extraordinary experience. If I were to be back in this situation, I wouldn't have asked anyone to help or told anyone about what I did. I have withdrawn life support before; I have stood and cried with families when their baby or child was dying. I have called them up and talked 6 months later. Rachel was different.

I have never lain awake at night wishing I hadn't helped to end the gasping. But I do think about Rachel and her mother a lot. I tried to finish the dying part to save Rachel from even a tiny bit of pain. I wanted to respect

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the agony of a mother whose dreams had vanished and who after 9 years of protecting her child, convincing the doctors that Rachel would grow and flourish, was now asking me to end the suffering of agonal gasping.

I never, ever wanted to make things harder. But after the whole story appeared in the paper and on the radio, it was complicated and hard for her. The reporters described Rachel as a "disabled" or "retarded" child. I know that hurt. Reporters banged on her door. In spite of all the pain, Rachel's mother made a tape to defend me to the police, to the district attorney, to the medical board.

In the end, I had my medical license suspended for a year, incurred a debt of over $100,000 in legal fees (none paid by the medical center), was not allowed to take care of any patients for 6 months, and I will never work in the PICU again. My name is in the National Data Bank, and I would have a huge battle getting hospital privileges anywhere but in the medical center where I still work, or a medical license in another state. But the biggest pain was knowing that this mom does not have a daughter, and I actually made the death more complicated and painful.

One thousand days later I think about this little girl who was the same age as my son. I think about her mother. I think about all the controversy and arguing about what is legal and what is not legal, about what is right, about slippery slopes. I have read books by Timothy Quill and Steve Jamison. I have had the privilege of talking to Dr. Quill. I cherish his concept of nonabandonment. I am left with the idea that every death is different, that no rules will allow doctors to escape the responsibility of figuring out what to do when a patient is near death. A plan can only be made with one patient at a time. And I get scared when I think of lawyers, judges, the Supreme Court being the decisionmakers. Legislation that governs end-of-life decisions at the bedside is difficult and complex, maybe impossible. Physicians should not expect or want the courts to settle this issue for us.

In writing about Karen Quinlan, Paul Armstrong (who represented the families of Karen Ann Quinlan and Nancy Ellen Jobes before the New Jersey courts) and BD Colen (Pulitzer prize winner, 1984, for coverage of the Baby Jane Doe case) wrote:

> Physicians and hospital administrators have repeatedly forced these cases into court, begging for guidance and freedom from civil and criminal liability. They have repeatedly been given both the guidance and the mantle of legal protection, and have been given it in such a way that they can return to the bedside and resume their traditional role. If they continue to rush to court every time they are confronted by a hard ethical choice, it becomes more and more likely that they will not like what they are told. While not all will agree with his view on the relative role of physician decision making and patient autonomy, we would all do well to remember the admonition issued shortly after the decision by C. Everett Koop, the pediatric surgeon . . . the Surgeon General of the United States: "There is no way that there can be a set of rules to govern this circumstance. Guidelines perhaps are possible, but not rules. I can think of no more tragic circumstance to come on the practice of medicine and no more tragic circumstance for a future patient to face than to have a legal decision made by someone in the field of jurisprudence who has not lived through these circumstances and who could not in a lifetime of testimony understand what the problems are and how they should be handled. His training, experience and his emotions have not been intimately involved with similar circumstances in the past where his decision

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> and his decision alone is the one that must answer all the questions, no matter how inadequately."[1]

Clearly, apart from any decision by the Supreme Court or other courts, physicians need to accept the challenge to maintain respect for patients' values. The most powerful argument against physician-assisted suicide and voluntary euthanasia is the possibility that patients may suffer because of it; the most powerful argument in support of physician-assisted suicide and voluntary euthanasia is that patients may suffer without it. In caring for our patients, we should remember that "suffering is ultimately a personal matter." I do wish I had never left Rachel's bedside Saturday night.

Recently, I heard a talk "medical care of the soul." I hope I gave Rachel's mother the time and respect to figure out how to continue to give her daughter, at the final moments, the same support and courage she had always given her. I hope I listened and understood what she needed and wanted at each stage: DNR, extubation, and Sunday morning. Did I really explore with her what her personal ideas and goals were? Did I explore these long enough to let her have the time and reflection she needed? I know that I had acted from the "heart"; that my decision was not from a viewpoint of power. But did I listen to Rachel's mother? Did I make sure that the decisions she made were ones she could feel peaceful about for the rest of her life?

For the most part, if we treat pain and anxiety well, we do not need to go further. But once in a great while a patient will need or ask for the "next step." It scares me that someone would say "no, never" and walk away. I am frightened that clinicians are afraid to give enough medication to treat treatable symptoms.

Law is different from medicine. Lawyers see things differently—I am sure of that at this point in my life. As a doctor, I see every patient as an individual and realize that often what is "right" for one is not for the next. And no rule will cover the extraordinary decision of one person in one situation. In contrast, lawyers claim that their goal is to treat everyone the same (we know that doesn't *really* happen), hold every citizen to the same standards, the same rules, the same law.

I no longer think that I can predict how my actions will be interpreted by other physicians, families, lawyers. I never expected to be reported to the DA. When I think of that now, I still shiver. Actually, I do not look at much in life as I used to before I met Rachel. I seem to be a lot more empathetic to suffering, less judgmental of the decisions others make that I disagree with. I don't think I ever gave the honor and respect to the concept of "grief" that I can now. What is wrong or right is not static. Yes, there are some things I would do differently—listening to Rachel's mother for more days, maybe. After all, I heard the neurologist, I saw the scans, I examined Rachel. But I was not the mom. Was I sure that she had every single question answered over and over again, as often as she needed?

The technology and choices—50 years ago, dying just wasn't so complicated, at least not as often as it is now. I don't think the district attorney will figure it out.

Note

1. Armstrong PW, Colen BD. From Quinlan to Jobes: The courts and the PVS patient. *Hastings Center Report* 1988;18(1):37–40.

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