Don't tell

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"Stop the ventilator, but don't tell my children."

Mr. Smith, a 55-year-old man dying of pneumonia and a large intracerebral hemorrhage, was being kept alive by life support. His wife of 35 years, her eyes red with tears, had made the difficult decision to let him die.

As we sat there, the room was silent save the whooshing cadence of the ventilator.

"They don't need to know," she said. "They've got enough on their plates right now."

What she did not want the children to know was that she had chosen to stop the ventilator but leave the endotracheal tube in place with room air flowing so it appeared Mr. Smith was still being ventilated.

"Why don't you want them to know?" I asked.

"I don't want them to know because they'd think I killed their daddy, that's why. I already spoke with them, and they wouldn't agree to stop the ventilator and let him go. I just couldn't live with them thinking I killed their daddy."

"But they might be suspicious because they won't hear the venti…"

She interrupted. "Doctor, please. He's dying, let him go in peace and with some dignity."

I understood what she wanted. Eight years ago, as my wife lay dying of advanced scleroderma, renal failure, gangrene, and disseminated intravascular coagulation, I gave permission for the cardiologist to deactivate her pacemaker and defibrillator without my daughters' knowledge (they were 23 and 20 years old). I did it when they went to the hospital cafeteria for lunch. There was no hope for her survival, she was suffering, and it was time. It was the hardest decision of my life. But my heart forbade me from telling them, for they looked at the pacemaker and defibrillator as life-saving devices. I imagined that's how Mr. Smith's children felt about the ventilator.

The ethics committee and legal counsel had already given their opinions, and they both agreed that Mrs. Smith had the right as legal surrogate to make decisions for her husband without consulting the children—including the unusual method of stopping the ventilator. Still, some of the intensive care staff worried about the lack of honesty with the children, and had consulted me to review the particulars of the wife's decision.

One nurse was quite vocal. "Dr. Rousseau, it isn't right. If I put myself in those kids' place, and I found out that my mother withdrew a ventilator from my father without telling me, it would affect me until the day I died." Others nodded in agreement. I cringed, wondering what my daughters would say if they knew what I had done.

The intensivist was of a different opinion. "We've worked hard to get to where we are, let's just withdraw the ventilator without telling the children. Do we really want him to linger in the abyss between life and death if the children refuse withdrawal?"

Both were good points, and both had merit. And legally, there was no question, the wife had the right to make the decision. But what she wanted was seen as deceitful by some intensive care staff, and as such, they had moral issues with the unfolding plan.

I asked permission from Mrs. Smith to visit the children in the waiting room if I promised not to disclose her plan. She approved, and as I entered the waiting room, 4 children sat huddled together in a corner of the room. The oldest slept sitting up while 3 others napped in small fold-out beds. They were all adults, aged 30, 28, 26, and 25 years. I interrupted their slumber and introduced myself and asked what they knew about their father's medical condition. They told me they knew their father was critically ill and likely not to survive. But the youngest, with tears in her eyes, said, "Daddy is strong, he can make it. God is gonna help him." Like many in similar situations, they were hoping for a miracle through the goodness of God.

After I left them, I organized a group meeting with nursing staff, the intensivist, the ethics committee representative, and the chaplain. The goal was to discuss staff concerns and to develop a uniform strategy. After 45 minutes, an alternative plan was proposed and agreed upon by everyone. For the benefit of the children, we would offer a time-limited approach to care: continue what we were doing for 3 more days, and then, if there was no improvement, withdraw

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Names and parts of the vignette were changed to protect privacy.

the ventilator. Moreover, everyone—Mrs. Smith and the children—would understand the ventilator would be withdrawn. There would be no deception. Granted, such a plan would entail more expense, and some argued, would border on the same slippery moral grounds as Mrs. Smith's scheme. They contended it would be analogous to a "slow code"—trying to preserve life, but not really. Still others insisted that Mr. Smith would be forced to suffer more by delaying withdrawal, although I was certain Mr. Smith had long ago left his body and was on another journey, and would not suffer. But for all of the concerns, it was agreed that this plan would allow a measure of honesty, and hopefully contribute to a guiltless grieving process for Mrs. Smith.

The intensivist, with my support, then met with Mrs. Smith, and proffered the option garnered from the staff meeting. Mrs. Smith pondered the proposal for a while, but refused and asked that we stop the ventilator that day—no more delays. We agreed, and after another meeting with staff, it was decided it would be best to stop the ventilator later that day when the family routinely gathered at bedside. We notified Mrs. Smith of the plan, but did not tell the children.

As the day wore on, and all watched the clock, the time arrived for the family to visit. The respiratory therapist quickly turned off the ventilator just as Mr. Smith's family entered the room. As they settled in the chairs and quietly chatted bedside, the chaplain stood down the hall with the intensivist by his side. Nurses watched from the nursing station. I sat in the computer alcove just outside the room. Things looked calm, but they were far from it.

Staff watched the clock and counted the minutes. Five, then 10, then 15 minutes. We all began to wonder and question. Suddenly, the monitor flashed a flurry of premature ventricular contractions, then a brief run of ventricular tachycardia. There was a pause, then another run of ventricular tachycardia, followed by ventricular fibrillation, and then asystole. The nurse entered the room, trailed by the intensivist, the chaplain, and myself. The children lay on their lifeless father, as Mrs. Smith caressed his stilled face.

What was said in the room was a passing blur. I know I offered my condolences and provided presence, hugs, and my own tears. But for a moment, I was back in another intensive care unit 8 years earlier, watching another monitor trickle to asystole, hearing my daughters' cries fill the unsettled silence.

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