The intolerable burden

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*Do not go gentle into that good night
Rage, rage against the dying of the light*

—Dylan Thomas

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I never got to know the real Margaret during the few days I helped care for her. She was a patient on the internal medicine service and I first met her on a Saturday morning. Walking into her room, I couldn't see her at first—the bed was surrounded by 3 tall young women and an older man. Two were nurses and the other 2, as I soon discovered, were her husband and daughter. As I got closer I could see all 4 were engrossed in an effort to prop her up on the side of her bed so she could dangle her feet. There had been several attempts but none successful. She kept collapsing like a limp rag doll.

The resident seeing consults with me provided the details of Margaret's story. She was a healthy 80-year-old woman who lived with her husband and not far from their daughter. Margaret was independent before her admission for a knee replacement. The day following surgery she was able to walk with a walker. On the second postoperative day, she awoke with weakness of her arms and legs, which worsened rapidly. By the third day, she could barely move.

"The two neurology residents who tried to see her last evening were asked to leave by the husband, saying his wife was too weak and sick for them to check her," said my resident, explaining why the evaluation included only a sketchy examination.

The resident and I joined the mix hovering around the bed. It was now the fourth day after her surgery. The 2 nurses were again trying to get her to sit in her bed, its head now elevated. She was a tall, thin woman, whose wrinkled cheeks puffed in and out like a set of rapidly moving bellows. Her short gray hair was more disheveled than curly. She did not want to lie back with the head of her bed raised.

"That doesn't help my breathing," she gasped. It seemed she was accustomed to being in charge. "Let me sit on the edge. Dangle my feet." Her words and breaths erupted in short rapid surges.

Even with 2 nurses supporting her, she kept crumpling back into the bed. She was breathing well enough for the moment but it wouldn't last much longer. A few minutes later she repeated her demand.

"I think you're too weak to sit on the edge of the bed," I responded, interjecting myself into the conversation. I wasn't sure that she comprehended what I'd said. She was focused on her breathing and trying to get comfortable. Her daughter was doing most of the talking. She looked worried as she went over the details of Margaret's illness.

The clinical facts strongly suggested that she was in the early stages of a rapidly progressing Guillain-Barré syndrome. Her shortness of breath would require prompt attention. "No breathing tube," she panted. "No artificial ventilation."

From the Department of Neurology, University of Iowa, Iowa City.

Her husband nodded his head. “We decided that years ago.”

“Too many older people get them and they never seem to help,” the daughter explained. “They just make the suffering worse.”

Her poor expiratory volumes made intubation necessary and her husband finally agreed to proceed despite Margaret’s protests. Nerve conduction studies done several days later showed normal muscle action potential amplitudes on electrical stimulation at the wrists and ankles as well as prominent conduction blocks, consistent with inflammation and the loss of myelin. Her nerves still being intact predicted a good prognosis for recovery.

Once intubated and settled in the MICU, Margaret began receiving IVIg over the next 3 days. She also required treatment for new-onset fluctuating hypertension and atrial fibrillation that were likely complications of the Guillain-Barré syndrome. She was kept sedated most of the time but when awakened she would complain about the endotracheal tube.

Her son arrived a few hours after her intubation and every morning there were long discussions about Margaret with the 3 family members. Each time I stressed the good prognosis, that she would likely make a good recovery, if not a complete one.

Each day they would ask, “Do you think she is any better?”

Each day I would answer, “We haven’t had enough time yet. We need to be patient. It will likely be a few more days for the IVIg to take effect and the damaged insulation of her nerves to repair.”

The conversation always ended with the same question. “When does the tube come out of her throat? She says she wants it out.”

“I hope in a few more days,” I would answer, “as soon as she is able to breathe not just better but safely on her own. It’s protecting her life.” I kept underscoring the good prognosis and the importance of the mechanical ventilation.

That was the discussion 2 days after completing the IVIg. A few hours later, a member of the MICU team called.

“The patient wants the ET tube removed and the family supports her wish.”

“Please let me talk to Margaret and her family first. I’m on my way up,” I said. I was surprised. Our earlier conversation that morning didn’t seem headed in that direction.

“You’re too late. We already removed the tube. The palliative care team is in the room right now.”

Overwhelmed, I placed the telephone receiver in its cradle. If only I had been in charge of Margaret’s care and not just the

consultant, I thought. I’d have tried dealing with the problem differently. I remembered the identical dilemma that occurred some years earlier. With the help of the family minister, I convinced an elderly woman and her daughter to continue mechanical ventilation for a few more days. The IVIg proved effective and she walked out of the hospital 2 weeks later. It was all about bargaining for more time.

In the MICU, I waited outside Margaret’s room for the palliative care physician to finish her visit. Later, we would discuss our different opinions. She would write in the chart that “the primary neurology team had a high level of confidence that the patient could make a meaningful, even if not complete, recovery. We discussed that the burden of treatment is different for every patient, and for this patient intubation crosses a threshold that she has said multiple times in the past she wanted to avoid. We discussed that each patient has the right to decline any treatment that, in the patient’s opinion, has more burden than benefit.”

That pretty much summarized the immediate quandary. It all came down to burden and benefit. Margaret understood the burden clearly. The burden was now—the discomfort of the tube and her inability to move or speak. She had been clear in her wish for no mechanical ventilation. She must have felt that the endotracheal tube and the ventilator were the precursors of death.

While the burden was clear, I was never convinced that Margaret understood the potential life-saving benefit of the assisted ventilation, the IVIg, and the MICU care. She always seemed too agitated to fully comprehend that what we were doing was likely to be short-term. I was confident that her family understood the possibility of a good and speedy remission, even though it must have seemed like an impossible dream. Margaret’s repeated demand likely fueled their uncertainties and, finally, their agreeing to discontinue respiratory support. Still, in my discussions with the family over the prior few days, my major focus to them was my optimistic prognosis.

I wish the team caring for her had decided to increase her sedation and maintain our course of action, but they decided otherwise. I wish they had talked to me before making their decision, but they didn’t. They must have fully agreed with the statement made by the palliative care physician that the burden was greater than the benefit.

Even with the tube out, the primary MICU team was not willing to negotiate with Margaret and her family. We might have tried oxygen instead of morphine for a few days. It might have kept her alive for the time needed for the recovery to begin. We could still treat her cardiac problems. She died later that evening.

I will never know if the patient and her family made the wrong decision, although I think they did. The nerve conduction

blocks remain indelibly imprinted in my mind. The patient and the family surely have the right to make decisions regarding medical treatments. But how proactive should the physician be when he or she believes the patient is making the wrong decision? When does the physician become the patient's keeper? How assertive should the physician be to affect a compromise?

Although in our current cultural climate, the wishes of the patients and their caregivers are paramount, this assumes they are really well-informed and can make good decisions. In a crisis, that can be challenging. The paternalism of another

era seems no longer appropriate: yet we are not always consistent. We will use all means to save patients who have attempted suicide despite a suicide note or verbal statement expressing their desire to die. I believe there are moments when physicians need to be forceful in influencing the decision-making process, especially when the patient's judgement appears flawed and prevents the strong possibility of a good outcome.

As I left after my final visit, the family thanked me for my time and effort. Maybe it was time for Margaret to go, I mused. Maybe 80 years is enough for anyone, but I didn't think so.

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