

### Autonomy and *ars moriendi*

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“How could her family just let her die? It’s not their decision to make. Amanda’s an adult—she’s 23 years old—and if she wants a heart transplant, she should get it. It’s her choice.”

The meeting with Amanda and her parents in the ICU had just ended and I felt enormous sadness. Amanda and her mother had cried much of the time. Her father, visibly agitated, had stormed out halfway through the meeting. I’d sat in my office with the three of them many times before but we’d never had such a tense exchange. Lisa didn’t know them the way I did. They were a fun-loving family who, until recently, had coped with Amanda’s downturns reasonably well.

I would have preferred some time alone to recover from the turmoil I felt, but Lisa, one of our best residents, needed to talk through what had just transpired. “I know it’s not easy or straightforward, Lisa, but why do you feel so negatively toward Amanda’s parents?”

Lisa hesitated. “I’m really not sure—I know that they love her and have made a lot of sacrifices to care for her. But when I was alone with Amanda and explained that her heart wasn’t strong enough to keep her alive, she said she didn’t want to die. I think she wants a heart transplant. But you heard her parents. They’re opposed. They want to take her home even though her cardiologist told them that Amanda would be dead within a matter of days. Amanda might live several years despite her Friedreich’s ataxia if we restore her cardiac function. Knowing her prognosis, the transplant team pushed to get her to the top of the list for a new heart.”

In the 10 years I had taken care of Amanda, I had learned a good deal about her and her parents. Raised in a small agricultural community, Amanda had given up trying to contend with her limitations and had grown more secure in the comfort of her home. She had never tangibly pursued her dream of living alone. Something always seemed to get in the way. Now, as a young adult who needed help in doing even simple things, she was confused and conflicted, wishing she didn’t need constant assistance yet comforted and reliant on her parents’ unwavering support.

Amanda had asked only a few questions of the cardiologist and me in the family meeting. Both she and her parents understood that the dobutamine dripping into her vein was keeping her heart going and that without this medication or a new heart, she would die. She cried softly. “I’m so confused. In mo-

ments when I feel very sick, I just want it all to end. But I’m afraid to die and at times when I feel better, I want to live.”

Amanda had turned to her parents. “Mom, dad, what should I do?” As her parents struggled to answer, I thought of the many conversations all four of us had had over the years as Amanda had evolved from a mildly ataxic teenager into a wheelchair-bound adult whose speech was hard to understand and who relied on her parents to help her dress, eat, and use the bathroom.

Amanda’s mother and father were overwhelmed by the demands of taking care of their chronically ill daughter and by their own feelings of inadequacy. They were also confused and resentful of the doctors who had given Amanda the illusory hope that a heart transplant would be her oasis. Even though they had always tried to honor Amanda’s wishes, in the end they knew that Amanda would count on them to make this impossible decision. Their priority had always been to protect her and to ease her suffering. They couldn’t understand why some of Amanda’s doctors encouraged a procedure that would require even greater monitoring and medications, no independence, and a life that was bereft of anyone’s definition of quality.

Ironically, nothing was said in the room that day that sparked my understanding. I couldn’t let go of what I saw as I looked into the eyes of Amanda and her parents. Compared to all the other times we had been together, the three of them looked drawn and exhausted. I realized that we had unwittingly helped to paint them into a corner. Amanda’s parents were going to feel guilty and remorseful no matter what decision they made. I knew there were no villains and that Amanda’s parents desperately needed our support no matter what they decided.

Unclear as to whether Amanda would opt for a heart transplant, Lisa and I were relieved to leave the charged atmosphere so we could work through our own conflicting emotions away from Amanda and her family.

“Lisa, what do you suppose Amanda’s life will be like if she gets a heart transplant?”

“For one thing, she won’t be short of breath, and she’ll have more stamina. More importantly, she’s too young to die and a heart transplant could extend her life for years.”

“What about her increasingly frequent choking, something the family says terrifies them when they feed her?”

"I suppose she will need a feeding gastrostomy pretty soon but that's easy to arrange. It seems to me that if Amanda's family doesn't want the burden of taking care of her in their home, they could arrange for her to live in a nursing home. Shouldn't she have the right to choose that option? The palliative care team talks about helping patients have good deaths—*ars moriendi*—but Amanda's not ready to die. We're not supporting her wishes."

"I can't imagine that Amanda would want to live if it meant being away from her parents in a nursing home. They have been such a critical part of her life. Who close to you has had a good death?"

"My grandfather Eddie. He lived a full life and died in old age. My grandmother had died a few years before, and he missed her terribly. He refused to go to the hospital when he became ill and wanted to die at home. The whole family understood and honored Grandpa Eddie's wishes."

"So, why do you feel so differently about Amanda? She has a loving family just like yours. Because we can neither cure her nor give her the life she wants, her family seeks to provide her comfort and security in their home."

"All of us expect to bury our parents. But it's so different when it's your child. We can't improve her neurologic degeneration, but she's young and wants to live and a heart transplant can make that happen. Isn't that what medicine is all about? It's not as if she's totally paralyzed. She can still do a lot of things. She can think and feel and communicate, so why not go ahead with the transplant? Amanda's parents seem unwilling to listen to other points of view and keep repeating that they are concerned about the quality of Amanda's remaining life. I worry that they're more worried about how taking care of her with a new heart will affect their own lives."

"Her disease does affect their lives every day. Like it or not, Amanda is dependent and wants her family to make decisions for her. Since that's the case, maybe we should support her parents even if we disagree with them."

"I understand that Amanda has never been eman-

ipated from her family but what if the circumstances were different, and Amanda were older and married? Would she then be on equal footing with her loved ones and have the autonomy to make her own life and death decision?"

"Everyone's situation is different, so there's no roadmap we can readily follow, but I remember a patient's situation that may partially speak to your question. Several years ago I was treating Hank, a middle-aged truck driver who developed ALS. I always looked forward to office visits with Hank and Marcy, his wife. They shared an earthy sense of humor and were incredibly frank with each other as well as with me. No discussion was out-of-bounds. As Hank weakened and needed the same kind of care as Amanda, Marcy arranged to work inside their home so she could keep working, hold down expenses, and still care for him. Their life together in the last year was particularly hard as Hank had very little remaining movement and needed help to do the simplest task. In spite of these limitations, both of them always seemed upbeat and playful when they came to see me. They were deeply in love and didn't let Hank's illness disrupt that bond. Although Hank had repeatedly volunteered that he didn't want his life prolonged, when his breathing began to fail, he became frightened and had a change of heart. I can still hear Marcy's seemingly selfish, yet totally honest response when Hank hinted that he might want to be on a ventilator: 'Henry, you can't do this to me. You promised me you wouldn't bankrupt us. I've made a lot of sacrifices for you, but if you go on a ventilator, I'll be left destitute when you die.'"

Lisa thought a long while before responding. "The end of life is more complicated than I was taught or ever imagined. Even in dying there are trade offs. Is it a dying person who gets to make autonomous decisions or his or her loved ones?"

When I told Lisa that Hank ultimately chose not to go on a ventilator, she seemed comfortable with his decision. But Lisa hadn't taken care of Hank. The next day she learned that Amanda would not have a heart transplant and was going home with her parents.

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