

## Silvia's blessing

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The first thing I noticed was Silvia's rocking. Back and forth, back and forth, the faux leather of the chair squeaking with each forward thrust of her diminutive, skinny frame. Then her huge sunglasses, much too big for her face, framing long black hair. And her teeth—white and protruding, but too large for her slender face and small mouth. She looked to be 12 or 13, but I wasn't sure.

Her aunt Beatrice sat next to her, smiling. Silvia's mother lay comatose and dying in the bed next to them, her liver and kidneys failing secondary to metastatic breast cancer.

I was there to help guide Beatrice in making some hard decisions, as the hospitalist had reached a decisional roadblock regarding further care.

"I am the caretaker for Silvia," said Beatrice. "She is a brilliant child. She loves music and sings beautifully." Then she silently mouthed the words, "She's autistic."

I nodded, but knew very little about autism. I felt ashamed I didn't know more, but imagined someone with autism looking and acting exactly like Silvia.

"Can you sing for the doctor?" Beatrice asked.

Silvia smiled and grunted a laugh, still rocking back and forth while eating a salad in stuttering moves. Certainly, a small salad was not enough calories to sustain Silvia's caloric needs—I could imagine 30 minutes or more for her to finish the small Styrofoam plate. By then, she would have burned all the calories and more that she just ate.

Her aunt must have read my mind, and said, "She gets liquid supplements."

Silvia stopped rocking for a few seconds, put earbuds into her ears, and turned up the music.

Beatrice looked at me and spoke softly. "Silvia is an only child. She needs her mother. Her father left 10 years ago."

Silvia's mother was only 35. I guessed she had maybe a few days to a week to live. I suggested we go to a conference room to talk about goals of care, as there was no advance directive and she was still full resuscitation.

As we entered the conference room, Beatrice immediately informed me that they were devout Catholics, and that God was in control, not doctors,

so she wanted everything to be done. The hospitalist had had this same discussion with Beatrice before, so she was prepared. In Beatrice's mind, "She is going to die" was distinct from "She is dying," and Beatrice was clearly anchored in the former. She was reconciled to her sister's death, just not at this time.

Still, I spoke of quality vs quantity of life, of love and letting go, and of what Silvia's mother would want if she could sit up and talk to us. But try as I might, Beatrice remained resolute in her desire for aggressive care. The hope for miracles, the invoked power of God and religiosity, and the grip of disbelief and denial pulled at her heart. She hoped for the best, but did not want to think about, let alone prepare for, the worst.

So I introduced an alternative, time-limited goal: to continue the intravenous fluids, antibiotics, and pain medications, and to reassess in 1 week, but to change to do-not-resuscitate. I really did not want to put this frail woman, and her family, through the trauma of futile resuscitation, or perhaps even worse, have her end up on a ventilator with even harder questions to answer.

"No, doctor, do everything. We want her to live, and doctor, God does perform miracles."

As I was getting ready to give in, Silvia suddenly pulled the earbuds from her ears, and spoke for the first time.

"Let mommy go to heaven."

I didn't know what to say, but without thought, asked Silvia to tell me what she had just said.

"Let mommy go to heaven."

"Your mommy wants to go to heaven?" I asked.

Silvia just rocked back and forth. I looked at Beatrice, who was now crying. I tried not to cry, but I couldn't help it. My tears started to flow.

"Let mommy go to heaven," Silvia said again, still rocking back and forth.

"Let mommy go to heaven," she said louder and more forceful.

"Let mommy go to heaven." She must have said it 10 times.

I looked at Beatrice. Through tears, she nodded her head yes.

"It's okay to let her go?" I asked. Beatrice nodded yes again.

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I told Silvia what we were going to do, but that it might take a few days for her mommy to go to heaven. I paused a few seconds to let my words settle, but Silvia never acknowledged what I said. Instead, she put her earbuds back in, and turned up the music.

It didn't take long. Silvia's mother died 2 days later. The nurses called to notify me, and as I entered

the room, Beatrice lay across the bed sobbing uncontrollably, but Silvia sat in the corner rocking back and forth as music leaked from her earbuds. She was not crying, and I wondered if her absence of tears was due to autism and the tangled emotions that complicate this disease, or the fact that she just knew it was time.

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