INSIDE STORY

LESS IS MORE

Talking About Dying

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The first thing I noticed was her belly. It protruded under the sheet in a perfect dome, as if she were holding an exercise ball on her stomach.

Her hands were at her sides. One of them was held and vigorously stroked by a young woman—her daughter—who looked up expectantly when I entered the room. She wanted answers, and her first question was why the fluid had not been removed from her mother's belly. At home, this had been done weekly, while she received chemotherapy for the pancreatic cancer that had wrapped itself around her intestines, studded her liver, and filled her belly with malignant cells.

As a palliative medicine physician, I had been asked to see her for pain. Reading through her medical record, I saw that she had been admitted to the hospital 5 days ago. Many specialists had been involved in her care, their notes laser focused on the particular body part or system within their area of expertise.

Hematology-oncology on her blood counts:

> "Patient discussed with housestaff and fellow. 62-year-old woman with progressive metastatic pancreatic cancer on FOLFIRINOX (cycle 9, 2/17/22) with pancytopenia. This is likely due to chemotherapy, but platelet decrease is a bit soon. Hemolytic workup appears to be negative. We agree with trending labs and we will check in to ensure they are trending up. Will update Dr M regarding patient's admission. Patient will need to see Dr M outpatient once discharged."

Gastrointestinal surgery with a plan for her intestinal tract:

- Reinitiate total parenteral nutrition
- Broad spectrum antibiotics pending cultures per ID recommendations
- Consult GI-biliary
- Primary care per MICU recommendations
- Will continue to follow

Interventional radiology on her ascites:

> "Placing pleurex catheter extremely high risk given patient low neutrophil count. If ANC improves and platelet count is higher, IR can be reconsulted. Will sign off."

Now meeting the patient, I marveled silently at this singular focus on her disease and organ systems. There was no mention of this woman in the bed in front of me. No description of her sunken temples or her bruised arms. No record of what she was hoping for or of what she was most afraid. Who would be the one to step back, to hit pause on the hospital treadmill, to gather the threads of her story together and start the conversation about what happened next? Who would be the one to tell her that she was dying?

I stepped out of the room to find the medical team leading her care.

"What is your sense of how things are going?" I asked the house staff.

"Her cancer is not responding to chemotherapy," one resident ventured.

"Her blood counts have not recovered," another offered.

"How about 'she is dying,'" I suggested, to sheepish and universal nods of agreement.

Dying was both too simple and too complicated to fathom. It meant that our diagnostic tools and hospital routines were suddenly not enough. I recognized the sense of helplessness and discomfort in the residents' eyes. All of the things that had been carefully counted and recorded and reported daily on morning rounds no longer mattered. Where did that leave us? Where did it leave the patient and her daughter? What could we offer now?

As a palliative medicine physician, I have been privileged to be part of many conversations about dying. I have watched how the words "you are dying" can burst the tension in a room like a needle in a balloon, allowing space for new hopes and fears to take shape.

A fear of being in pain. A hope to die at home. A fear of leaving a bill unpaid or relationships left unresolved. A desire to taste a sip of beer or lick a popsicle. To go outside and see the sky. To sit on a front porch with a gun and shoot at the rabbits. Acknowledging death helps us refocus on living.

I have also noticed that talking about dying shrinks the distance between me and my patients. The experience of death is universal—there is no hierarchy involved. I have to put aside my medical knowledge. The daily reports filled with diagnostic test results and laboratory values that I carry around and can easily hide behind like paper shields become meaningless. Instead, I come armed with tissue boxes and prepared for tears.

My white coat does not protect me from the sadness of these conversations. I think about my own mortality. I reflect on a friend's recent cancer diagnosis and my grandmother's last weeks of life. I appreciate my daughter's hugs and my son's jokes more deeply. I text my husband to say "I love you."

Talking about dying reminds me that we can cry one moment and laugh the next. That people love each other fiercely and protectively. That grief can manifest as anger. That in the end, nobody cares about academics or politics, and everyone is searching for meaning and human connection.

The team and I returned to the patient's room later that afternoon. After asking permission, we shared the news with her and her daughter.

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"Tell it to me straight," she demanded. "Don't sugarcoat things."

"I think you are dying," I said, and then paused, allowing space for the emotion in the room. The medical residents and oncology fellow stood in a row against the wall, holding their collective breath and studying the tops of their shoes.

"Hell, how long have you known that?" the patient shot back.

It was not really a question so much as a plea. Because up until then, her clinicians had not been straight with her. They had focused on correcting laboratory values and diagnosing organ system failures. Up until then, no one had acknowledged where things were headed or what could not be fixed.

"I am so sorry," I said. We all exhaled.

And from there, things happened quickly. The patient was clear that she wanted the rest of her life back. She lived several hours away in the country, and she wanted to go home. There was a window in her living room that looked out on a meadow with horses. Her grandchildren would be able to visit. Her pastor could stop by. We began aggressively treating her pain and arranged for hospice services to meet her at the house. She left in an ambulance, her daughter still holding her hand.

For me, this was something that we could offer. Not what any of us hoped for, but not nothing. When I checked in afterward with the medical team, they agreed. Rather than feeling like we had let the patient down, we felt like we had held her up with what we had to give—our honesty and our compassion.

Talking about dying gives us all permission to live. Gratefully, unapologetically, and in the present moment. This is a small gift—for our patients and for ourselves.

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