

Learning to Care at the End

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The chest radiograph is stunning. Metastatic tumors appear like cotton balls, stark white opacities where there should be only black air, and the faint white brushstrokes of ribs. They tell the story before we even see the patient. Maddy is only 15, and her cancer has progressed.

Our team (pediatrics residents, an attending oncologist, a nurse practitioner, and me, a third-year medical student) gazes at the image in silence. Maddy has been receiving chemotherapy for months, coming to the hospital for tune-ups when the side effects become overpowering. This time, it has become difficult to breathe. We were hoping the radiograph would simply show pneumonia. But these are cancer cells and they are multiplying rapidly.

We crowd into her room for morning rounds. Maddy and her mother nod when they hear that the cancer has progressed. They are not new to this; they know her treatments and the corresponding questions. No, she has no mouth sores, but her feet feel numb. She is not surprised that her hemoglobin is low, but she doesn't feel weak enough to need a transfusion. Maybe tomorrow.

In the afternoon, the conference room fills for the weekly meeting. Residents, nurses, medical students, social workers, child life specialists, and a chaplain. As we wait for the attending physician to arrive, discussion turns to Maddy.

A resident reviews this morning's bad news. The social worker remarks that Maddy and her mother remain upbeat. After a pause a nurse speaks up: What is the prognosis? How much time is left?

Uneasy glances skitter around the circle. The nurse practitioner clears her

throat. The goal is to get Maddy home for the holidays and her 16th birthday. Right now, it looks like that will happen.

Still, another nurse presses, isn't it time to start planning, to have the difficult discussions? There are murmurs of agreement. No one volunteers. The attending doesn't like those conversations, the nurse practitioner says. He avoids them until the very end. She doesn't like them, either. Nurses fiddle with stethoscopes. Residents glance at their watches.

Someone turns to the chaplain: could he talk with Maddy and her mother, find out their wishes? He nods slowly. He will go.

The next morning's rounds have finished. Residents write orders and notes. Nurses buzz from room to room. The chaplain slips from Maddy's door and heads down the hall.

Suddenly, Maddy's mother is behind the work station, slumping into a chair next to Maddy's nurse. She looks spent, but her voice is defiant. Why is the chaplain bringing up palliative care? Why? Maddy is a fighter. She talks about shopping for a prom dress next spring. She is not ready to give up.

The nurse murmurs soothingly as the mother's voice slides toward pleading. The doctor has said nothing about giving up. Her voice breaks. He has said nothing at all.

I find Maddy's obituary a few weeks later. I've moved on to a different rotation, different diseases and patients, but Maddy and her mother have stayed with me. She died in the hospital just before Christmas. She didn't quite make it to 16.

Years later, I still wonder what discussions occurred between the

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attending physician and Maddy's family. During my training, I have repeatedly witnessed how communication can break down near the end of life. Through a combination of avoidance and misunderstanding, we often fail to equip patients with information and options that may affect the way they choose to live and to die. We might hand-wave around prognosis, focus on curative treatments when a cure is extremely unlikely, or avoid discussing palliative care or hospice care until little time remains to decide. We might let our own insecurities affect the way we interact with these patients and their families.

Perhaps Maddy's doctor did eventually discuss these topics with her and her family. Regardless, I have met numerous other families facing life-threatening diseases whose physicians, from a variety of subspecialties, have sugarcoated, danced around, or outright avoided these topics. I have also met families who, despite numerous such discussions, were unable to acknowledge the possibility of any outcome other than a cure. In these situations, the principles of palliative care can help to better facilitate communication and mutual understanding.

Palliative care is the field of medicine that focuses on maximizing the quality of life of patients and families facing serious illness, with an emphasis on the prevention and management of pain, whether physical, emotional, or spiritual.¹ Hospice is one subset of this field that provides care to patients nearing the end of life with an emphasis on "caring rather than curing."² Palliative care, however, can be applicable to patients early in the course of illness, in conjunction with therapies intended to prolong life, and can provide a platform for discussing families' preferences long before end-of-life decisions need to be made.

There is little debate over the importance of palliative care. The American Academy of Pediatrics'

2000 policy statement asserted that "all general and subspecialty pediatricians . . . need to become familiar and comfortable with the provision of palliative care to children."³ With more than 50 000 children dying in the United States each year, and more than 500 000 facing life-threatening conditions,⁴ every pediatrics resident will likely care for children who are severely or terminally ill.⁴ However, most residents receive inadequate training in critical palliative care principles, such as assessing patients' and families' goals or introducing hospice as an alternative to curative therapy.^{5,6} Program directors agree; less than 40% feel that graduating residents are competent in this field.⁵ Indeed, one children's hospital found that a wide range of staff members, including attending physicians, felt inexperienced at communicating with dying children and their families.⁷ A recent case review of 20 children with life-threatening or life-limiting illnesses found that only half had discussions regarding their preferred location of care and of death.⁸

Like Maddy and her mother, children and their parents look to medical teams for guidance as they navigate the complex experience of illness. Given the choice, some families will opt to continue aggressive treatment, others will choose hospice, and still others will choose something in between. No choice is wrong, so long as decision-makers fully understand all options. But understanding can only be achieved through honest, open, and ongoing communication. For this to happen, we need to be present for patients, supported by a set of skills and previous experiences. Such competence can only come from training, exposure, and reflection.

Palliative care can often be misinterpreted by families as the medical team "giving up" on their children. If we are to destigmatize palliative care in the minds of

patients and families, we need to train pediatricians to engage families in critical, challenging conversations. These skills, especially techniques for effective communication in emotionally charged situations, need to formally enter the medical training curricula in both theory and practice. As trainees, we need to feel the angst and uncertainty of difficult conversations and learn to push through our discomfort and tolerate suffering. With a concerted educational effort and knowledgeable mentors to guide us, we can learn to best care for our patients even at the end of life.

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