

Making a Safe Space Possible



Amy E. Caruso Brown, MD, MSc, MSCS

From the Department of Pediatrics, and Center for Bioethics and Humanities, State University of New York Upstate Medical University, Syracuse

The author has no conflicts of interest to disclose.

Address correspondence to Amy E. Caruso Brown, MD, MSc, MSCS, Center for Bioethics and Humanities, SUNY Upstate Medical University, 618 Irving Ave, Syracuse, NY 13210 (e-mail: brownamy@upstate.edu).

ACADEMIC PEDIATRICS 2017;17:343–344

MY NEWEST PATIENT was Michael (not his real name), a 16-year-old boy with a self-assured politeness that had charmed the nurses and impressed the chaplain. When I entered the room, after a brief knock and even briefer pause—more ritual than functional—he was sitting on the edge of his bed with his back to the door. His parents and sister formed a tight circle around him, their heads bowed in prayer. Only his father looked up and I gestured to him to continue. When they were finished, I pulled up a chair to talk about sperm banking.

A day earlier, Michael had presented to the emergency department complaining of difficulty breathing. A chest x-ray followed quickly by a computed tomography scan identified a large mediastinal mass, and he was admitted to our pediatric intensive care unit. His history of several months of fatigue, weight loss, and night sweats suggested Hodgkin disease. Impressive cervical lymphadenopathy had made an urgent biopsy under local anesthesia feasible. One of my colleagues, the pediatric oncologist on-call overnight, conveyed the results, confirming the diagnosis and the initial treatment plan to Michael and his parents.

After taking over his care from my colleague, I stopped to speak with the resident on call and explained to her the urgency of discussing fertility preservation before starting chemotherapy. She stared at me skeptically, a reaction I recognized as well as remembered. A new diagnosis of cancer is an emotionally fraught time for families who must also struggle to grasp information, in just a few days, that physicians spend a decade or more learning—to understand something about genetics and cell biology, perhaps for the first time ever, to weigh short-term risks and long-term toxicities of multiple treatment modalities against uncertain outcomes, to contemplate enrollment in clinical trials. It can also be a difficult time for residents, who are themselves trying to master the art as well as the science of medicine: to learn not only the pathophysiology

and treatment, but also how they can help families the most. The idea of asking families to put aside hope and fear and be eminently practical—to plan for a future that has abruptly become tenuous—can appear bizarre and irrational, or even insensitive.

As a pediatric oncologist, I sometimes think my most important role is to help families understand that their child's diagnosis is not the end of their lives—that, in most cases, there truly is a day after tomorrow. Nothing does that quite as singularly as the conversation regarding fertility preservation. I needed to encourage my patient to be able to imagine not just one, but many, possible futures, to help him understand what it means to keep a door open, while at the same time, validating his current feelings and respecting his choices and nascent autonomy.

In a perfect world, this would be a conversation held only after painstakingly building a rapport between physician, patient, and family, including a thorough understanding of their beliefs, values, and particular family dynamics. In my imperfect world, I needed the resident—cross-covering for the afternoon—to summarize the social history and hope it would give me a solid foundation on which to build trust, expediently.

The patient's social history had been pieced together from enough sources to feel a bit like a game of telephone. The parents had been away on a trip to visit prospective colleges with their daughter, and the young man had come to the emergency department with another boy of about the same age. The nurses described the other boy as a "friend" but the overnight resident referred to him as the patient's "boyfriend." The current resident was unsure whether this was fact or speculation but noted that the friend—or boyfriend—had not left the hospital until the patient was sleeping.

In the room, I sat down and encouraged Michael's parents and sister to take seats as well. I reviewed what they understood about the likely diagnosis and treatment and then explained the main purpose of my visit. Four pairs of eyes looked at me with surprise that quickly resolved into 4 different reactions. His father straightened a bit, shoulders rolled back—pride, perhaps, imagining his son

Amy Caruso Brown is an Assistant Professor of Pediatrics, Bioethics and Humanities, and the Co-Director of Foundations of Reasoning in Medicine at SUNY Upstate Medical University. This is her fourth narrative essay and her first in this journal.

as a father himself someday. His sister blushed and fidgeted with her jewelry. Michael looked out the window. “I don’t want to have kids,” he mumbled. His mother winced and bit her lip. “Do you want us to leave?” she asked. She watched her child intently, but he shook his head.

I stumbled, searching for the right words to connect to this young man and his family in this crucial moment.

I started again, prefacing that this was absolutely his decision to make and that there were no right or wrong choices. Then I said, “I just want to encourage you to think about how you might feel if someday you meet a girl—” His withdrawal was subtle, but I realized the misstep immediately. In the space of a heartbeat, I weighed my words—I didn’t know how he identified himself or what his family knew, and all I could say about their values with confidence was that they believed in a higher power—and then I added “or a guy... and they want to be a parent with you.”

For the first time since I broached the subject, Michael met my eyes and slowly nodded.

My approach that day wasn’t the most articulate or sensitive of my career but it was a turning point in how I

communicate with patients and families. In that moment, I understood more about the dance that all pediatricians do to balance the needs of parents with the needs of children and, especially, adolescents—my split-second decision to add 3 little words reflected the bone-deep recognition that creating a safe space for my patient, a young man wrestling with a new cancer diagnosis and possibly also his sexual orientation, was my first and most basic duty as his physician. Now, years later and a medical educator who primarily teaches bioethics, I recognize that, with Michael, I had practiced what I now preach: to put a patient’s best interests first, and ahead of my own discomfort.

ACKNOWLEDGMENTS

The author thanks Jordana L. Gilman for her review of this narrative and her willingness to educate her teachers about the importance of inclusive language.

Authorship Statement: Amy E. Caruso Brown conceived of the idea for this article and wrote the narrative.