

A Lovely Family...

Gitanjali Arora, MD, DTMH

A LOVELY FAMILY... “What a lovely family!” we said in unison as we walked into the hallway. The social worker, the resident rotating with our pediatric palliative care team, and I all smiled at this shared sentiment. The family *was* lovely. We had just finished our initial consult with the mother, father, and 5-year-old patient—a previously healthy girl now diagnosed with a brain tumor with an extremely poor prognosis. Although it was our first-time meeting, her parents shared openly about their process of medical decision making, their hope that she could have some quality time at home with her siblings, and their worries that they would not be able to protect her from discomfort. The patient herself added lively and imaginative stories throughout our visit, smiled widely to reveal her dimples, and wiped her mother’s tears as she kissed her on the cheek and reassured her that “everything would be ok.”

What else could we have said when leaving the room? They were truly a lovely family and the words to describe their pain and loss were perhaps too daunting to wrap our hearts around just yet. However, weren’t all the patients and families we had seen all day also lovely? Why hadn’t I walked out of the 12 other patient rooms that day with the same reflection? Was there something about this family that resonated with me in a particular way? Was it that they were “palliative-minded,” using many of the words we would have chosen to use to describe their hopes and worries about medical treatment? Was it the way they opened up to us so readily? Did their child remind me of my own? Or was it that this White English-speaking cis-gendered heterosexual family is my cognitive shortcut for what a lovely family looks like, even though my own family does not look like this. What would it mean that I had designated this family as lovely? Would I check-in on this patient and her family more often? Would I spend more time thinking about her symptom management and goals of care? Because I had determined that this family was “lovely,” would they receive better care

than all the other lovely families that I had seen that day where I had not recognized their loveliness?

I have learned that implicit bias, “the associations outside our awareness that affect our understandings, behaviors, and decisions” are pervasive, including among health care professionals. I have worked toward understanding how through my own associations, I am not able to hear the voices of my patients equally and, therefore, cannot provide healing and comfort equitably. Through global health work, I have been taught by patients and mentors that meaningful and ethical engagement across cultures requires cultural humility; the concept that emphasizes the limitations of our own cultural perspective and the inability to ever be fully competent in another person’s culture or experience. And I am increasingly aware that the view through which we hear and advocate for patients and families is undoubtedly influenced by our own cultural construct, and perhaps further limited by the predominant cultural identification of our team as non-Hispanic White.

The incident with this family occurred two years ago. That same day, I had spent the morning facilitating communication between the medical team and the mother of a teenage boy with a relapsed and now terminal illness. The medical team shared that the mother had refused the recommended medical plan, was difficult to work with, and was angry. Before meeting her, because of the words used, I could also infer that she was Black. Although palliative care is often consulted to help when there are difficulties in communication between the medical teams and families, the descriptors “noncompliant,” “aggressive,” “difficult to engage,” “not warm,” and “taking advantage of the health care system” were stereotypes I had most often heard used when describing Black mothers in our hospital.

When our palliative care team met with the mother, she spoke effusively about her son’s life: his accomplishments, his and her hopes that he would attend university, and eventually become a doctor. We watched a video of him

giving his commencement speech—we watched it twice. She shared her worries that the health system would not treat him fairly, that he would be given too much medication, or experimental treatment, or not enough treatment. Her mistrust of the health system may have been influenced by the long U.S. history of medical maltreatment of African American patients, and was being reinforced by the current inability to hear her. We understood from our colleagues that there was no treatment that would offer cure and yet we were describing her as noncompliant for refusing our medical recommendations. Regrettably, I had not left this patient's room remarking on the loveliness of his family. In the years since, and with the benefit of learning and continued reflection on my own

biases, I have often recalled the way this mother's eyes lit up as she shared her son's accomplishments and how he delighted in her pride. Truly, a lovely family.

Address correspondence to:
Gitanjali Arora, MD, DTMH
Department of Anesthesia and Critical Care Medicine
Children's Hospital Los Angeles
4650 Sunset Boulevard #170
Los Angeles, CA 90027
USA

E-mail: garora@chla.usc.edu