2018 Hope Babette Tang Humanism in Healthcare Essay Contest

First Place Medical Student Essay

Antoinette Esce

The man was running. One hand on his wide-brimmed black hat, keeping it pressed to his head. His handmade linen pants pressed against his thin legs. His temporary children's hospital ID badge flapping in the wind against his chest. The scene was almost comical; it was dusk, and he did not fit among the streetlights and cars and hospital parking lots. I knew this man. But I did not know why he was running.

Perhaps he was running to something. Maybe in search of nonhospital food or a bit of fresh air. Perhaps he was merely stretching his legs, which were otherwise bent in a seat next to a hospital bed. Perhaps he was running away from something. Maybe from the overwhelming hustle and bustle of a complicated life he had chosen to avoid. Or maybe from his child, in the tower behind him, who was slowly dying of cystic fibrosis.

***

I know this man, as well as one can come to know the father of a new patient. His son Jonah is 10 years old, gaunt and pale, with fingertips and toes swollen from chronic hypoxia, reminding me of the black olives I shoved onto my fingers as a child. He is cheerful and doesn't complain, except to confirm his mother's advocacy about his thirst or discomfort. His large and loving Mennonite family, speckled with cousins who have lived and died with cystic fibrosis, come in and out of his room, reading with him, cheering him up, and diligently providing the ritual of chest therapy every hour without fail. They know that Jonah will eventually die from his lung disease, and they do all they can to ease his suffering.

Still, Jonah presents to our emergency department in respiratory distress and an oxygen saturation half of what it should be. His family gets free medication from a different hospital, but can never make it to Jonah's follow-up appointments. They don't believe in accepting government assistance, because their life revolves around their religion, and they want it separate from the state. Their community is still paying off the bill from his last hospitalization.

The experienced pediatric pulmonologist says, "This is what cystic fibrosis looked like when I started fellowship." The care coordinator is distressed, because these patients can live well into middle age with aggressive therapies. The provider team is torn between the out-of-pocket expense of a now questionably beneficial, conventionally aggressive treatment regimen and the unnerving complacency of a more pragmatic approach. The social worker reflects that "if this were any other family, we would have already called child protective services."

The facts of this case are straightforward. We're looking at a 10-year-old Mennonite boy with severe cystic fibrosis, who has not been receiving the standard, rigorous, inpatient treatment protocols, presenting in respiratory distress. We were all looking at the same thing. But what did each of us see?

Some of us saw a helpless young boy, born into a world that he didn't choose, whose life and opportunities had been unnecessarily taken from him by his community. We saw a negligent family, letting their child die from a terminal, though treatable, disease. We saw a world and a culture that we couldn't begin to understand, a set of values that we rejected as immoral. How could they put their desire for a simple life above the health of their child? It was wrong.

***

2018 Hope Babette Tang Humanism in Healthcare Essay Contest

The Arnold P. Gold Foundation holds an annual essay contest to encourage medical and nursing students to reflect on their experiences and engage in narrative writing. The contest began in 1999 focused on medical students and expanded to include nursing students in 2018. Students are asked to respond to a specific prompt in a 1,000-word essay.

For the 2018 contest, students were asked to reflect on the following quote and share a health care experience with a patient or fellow clinician that led to a new, unexpected understanding or perspective:

> *"It's not what you look at that matters, but what you see."* —Henry David Thoreau

More than 200 essays were submitted. A distinguished panel of judges, ranging from esteemed medical professionals to notable authors, reviewed the submissions. Three winning essays from medical students and three winning essays from nursing students were selected, along with 10 honorable mentions. The winning essays were published on the Arnold P. Gold Foundation website (www.gold-foundation.org) and will be published in consecutive issues of *Academic Medicine* and the *Journal of Professional Nursing* in the fall/winter of 2018.

The contest is named for Hope Babette Tang-Goodwin, MD, who was an assistant professor of pediatrics. Her approach to medicine combined a boundless enthusiasm for her work, intellectual rigor, and deep compassion for her patients. She was an exemplar of humanism in medicine.

The Arnold P. Gold Foundation, which is celebrating its 30th anniversary this year, champions the human connection in health care. The nonprofit organization engages medical and nursing schools and their students, health systems, companies, and individual clinicians in the joy and meaning of humanistic health care, so that patients and their families can be partners in collaborative, compassionate, and scientifically excellent care.

A. Esce is a third-year medical student, University of Rochester Medical Center, Rochester, New York; e-mail: antoinette_esce@urmc.rochester.edu.

Acad Med. 2018;93:1804–1805.
doi: 10.1097/ACM.0000000000002449

Stopped at a red light outside of the hospital that night, watching Jonah's father running along the side of the road, I realized that I saw something different. His stance was resolute, his face was sad; he looked tired. Maybe he wasn't running from Jonah's illness or the hospital. Perhaps he was running away from us, our discomfort, and our judgmental stares.

***

I had been conflicted that afternoon. The narrative of neglect was convincing, but it didn't seem to fit with the devoted and loving family or the happy child for whom I had spent all day caring. How could they neglect him without scarcely leaving his side? Was he malnourished from an incapable family or because his pancreas was shutting down? Was his lung disease so severe because of stubborn parents or because the cystic fibrosis that ran in his family was particularly deadly? Was his family's approach to this illness truly wrong or was it just different? Didn't they have the right to treat it with culturally sensitive medical care?

I sat with Jonah and his family for a while. I saw a well-worn book at his bedside table. He told me that it had belonged to his many siblings before him. It comforted him. I saw his family's innocent fascination with the helipad outside his window. It made Jonah laugh. He told me how he wanted to go back to his farm, to his pony, to his home. I saw that he knew he was sick. I saw his mother's face set in resigned sadness, but laced with pride for the brave and mature boy in front of her. I saw a loving family, gracefully coping with tragedy. It was beautiful.

***

The red light had turned to green. Jonah's father turned a corner and was gone. I wondered what everyone else, in all of the cars around me, thought about him, in his foreign garb and robust beard. Stranger in a strange land. Mennonite man on a medical campus. Henry David Thoreau said, "It's not what you look at that matters, but what you see." But where was the truth in what we saw? I don't know. Probably somewhere in the middle. Somewhere between neglect and beauty. Somewhere hard to find.

I returned to the hospital the next morning, no surer about what I saw, only confident that there were many ways to see it. I went in to say hello to Jonah's family and handed them walking directions to a nearby park. "I hope you see something beautiful the next time you go running."

Editor's Note: The patient's name and other details have been changed to protect patient privacy.