

2019 Hope Babette Tang Humanism in Healthcare Essay Contest

Second Place Nursing Student Essay: Knowing Noah

Jessica Corcoran

It was in the early hours of the morning in the Newborn Intensive Care Unit (NICU) where I was completing my practicum hours during my final semester of nursing school when the nurses got a call that a mother would be delivering a baby with a rare, fatal brain defect. This particular defect is characterized by underdeveloped brain tissue, absence of the corpus callosum, and a single brain ventricle instead of the four ventricles typically formed during fetal development. Babies with this diagnosis usually do not live for very long and need extensive help with basic bodily functions. The nurses were all in agreement that this baby should not receive medical intervention because it would only cause unnecessary pain and not change the ultimate outcome. The parents were counseled about the disease and its prognosis. However, they chose for their baby boy to receive every medical intervention possible.

When Noah entered the world, he did not have a spontaneous cry. He required an immense amount of support to breathe and maintain his blood pressure. As he was being admitted into the NICU, his father sat nervously in the corner and remarked that he had never been in a NICU and had no idea what to expect. I secretly felt the same way, as I had no idea what to expect as a nursing student in this situation. Nevertheless, I sat and spoke with him, to try and alleviate his fears—and mine. I explained the procedures (intubation, central line placement, catheters) that were occurring and why they were all necessary to keep his baby alive. Noah's parents were unwavering in their decision to save him.

The first few hours of Noah's life were terrifying for the family, and for me as a nursing student with no experience in this type of situation. In those early moments, I felt angry at Noah's

parents for putting him through many medical procedures even though they knew that the outcome would be the same—inevitable death. He did not have enough brain tissue to sustain the basic functions of human life. I understood the science of it and could not understand the parents' decision to ignore that. However, the parents did not see science; they only saw their much-anticipated, well-loved son.

As the days progressed and Noah's critical condition stabilized, I continued to talk with the family, and I slowly began to understand their steadfast decision to try every medical intervention for their son. They longed for him to come home and discussed their dreams for his future and the zoo animal-themed nursery they hoped he would one day enjoy. This tiny baby was perfect to them, and they needed to know that every measure was being taken to assure he had a chance at coming home. They were not stubborn or insensible; they were scared and clinging

to the idea of “normal” that they had envisioned since finding out they were pregnant.

As the days in the NICU turned to weeks, they began celebrating small victories, such as days without a code blue being called and the weaning of his blood pressure medications. Slowly, their idea of a “normal” life with Noah was morphing into the NICU life they never expected. They made the NICU their home complete with pictures of extended family and stuffed animals from Noah's nursery.

A few weeks later, Noah's condition deteriorated as I feared it inevitably would. I was fortunate enough and honored to be able to participate in a meeting with Noah's parents, neonatologists, neurologists, and palliative care specialists as they discussed end-of-life care. The health care team pleaded with the family to see Noah's pain and allow him to pass peacefully.

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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 2019 contest, students were asked to reflect on the following quote and share an experience in which they or their health care team engaged compassionately and respectfully with a patient to help them feel accepted and seen.

I long, as does every human being, to be at home wherever I find myself. —Maya Angelou

More than 300 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 will be published in consecutive issues of *Academic Medicine* and the *Journal of Professional Nursing* in the fall/winter of 2019.

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 infuses the human connection into health care. The nonprofit organization engages schools, health systems, companies, and individual clinicians in the joy and meaning of humanistic health care, so that they have the strength and knowledge to ensure that patients and families are partners in collaborative, compassionate, and scientifically excellent care.

Please see the end of this article for information about the author.

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While the parents listened to the compassionate medical professionals discuss the option of withdrawing care so Noah could pass peacefully in no pain, they remained unwavering in their decision to continue aggressive medical intervention.

A few days later, it became obvious that Noah was going to die soon. He had maximum ventilator and blood pressure support, but all the medical interventions could not sustain life. The palliative care specialist was called once again, and I was able to witness and learn from this skillful and compassionate human whose daily job may be the hardest to do in health care. I watched how he acknowledged the parents' love for their

son and how they were being asked to bury their family's hopes and dreams along with their son. He validated the parents' fears that losing their son meant not just losing their past but losing their hopes for the future. The palliative care specialist was able to help the parents see that their baby's home was no longer on this earth, but the memories they had of Noah would always be with them. He was able to be a voice and an advocate for Noah. This time, the parents listened carefully and thought about their precious boy in pain and finally made the impossibly heartbreaking decision to let Noah go. Their idea of "home" for their baby had to change, and for the first time, they accepted the painful reality of their situation.

Surrounded by loving family and the health care team who cared for him for many months, Noah finally went home. Although this situation may not be considered a "success" story in the traditional sense, I consider it the best outcome for the little boy in the center of it all. We were able to advocate for a most vulnerable patient who likely would have passed cruelly during a resuscitation event. Instead, he was able to pass compassionately in the arms of his mother from his earthly home to the next. It was an honor to be in the midst of, and learn from, a healing team who cared immensely for both the patient and the family.

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