

2018 AAP and APA Ethics Essay Contest - *Honorable Mention*

Alkaline Water

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I disagreed with your family in most of the decisions regarding your care. There were times when I was antagonistic and times when they were in denial. Your parents were amateurs in this topic, as expected; and I was trying to re-member the four principles of bioethics. We had three en-counters and I believe at the end it was a successful disagreement, leading me to cultivate cultural humility and teaching me to avoid the death-end road that is hostility. I trusted them and they trusted me; this allowed us to let you go in peace.

Loss of equilibrium—the symptom that led to a diagnosis that would change the life of this teenager and his family forever; I never thought it would change mine. I met the family the day he was diagnosed, when a colleague resident asked me to translate for her a conversation that included words such as: tumor, urgent, intensive care, brain. The parents emigrated from South America 14 years ago, the same age as their son who was being diagnosed with diffuse intrinsic pontine glioma. I explained what was going on, getting back that staring look that you get when someone is speaking in a different language. This time the language was not the problem, both parties spoke Spanish. The problem was my lack of empathy; after all I was just translating and I had my own patients in my mind. Once at home I ran the episode over and over again in my mind, how I was asked to ‘drop a bomb’ to a patient that wasn’t mine. How could I have spent more time empathizing with the family? After all they were from the same country as I was. But the biggest question in my mind was, am I being culturally insensitive towards my own culture?

We received a notification by the emergency medical services (EMS): “We are coming with a 14 year old in septic shock, estimated time for arrival 7 minutes”. The patient had a respiratory rate of 10 breaths per minute, or even less. His forehead was warm and full of perspiration. We connected him to the monitor. His blood pressure was be-low the lower limit for his age. He clearly had septic shock with respiratory failure and the next step was to intubate. The intubation was successful, my first one in an acute setting. I came to the waiting room, with my forehead held high, to speak with the parents. The father held, in his sweating hands, a discharge summary from another hospital with the diagnosis of brain tumor. Once I started the interview I realized that he recognized me. Later I realized how important I was in their life. I had pronounced the words ‘tumor cerebral’ for the first time when their son presented with loss of equilibrium. The father explained to me how rough the last months had been, they had been hop-ping from one hospital to another. The main reason for this ‘hospital tourism’ was because doctors considered that palliative care with minimal invasive interventions was in his best interest, an idea that the parents refused completely. They were convinced that their son would wake up soon and become the same person he was over a year ago. They asked me my opinion, I think because they found comfort in my Spanish accent. I also agreed that palliative care was the best option, emphasizing that my opinion was that of a newly second year pediatric resident. They felt antagonized and I felt they were not respecting the child’s autonomy.

Autonomy is one of the hardest concepts to define in pediatrics. Who does it belong to? Undoubtedly, it is a moral norm of high priority in medical ethics. Nevertheless, some cultures will drift away from the Western concept of individual autonomy, in that they consider the family as the smallest unit for moral considerations. This family was trading the best interest of their child for familial interests, a concept defined by Ross as 'constrained parental autonomy'.¹ In this model, parental decisions that do not significantly increase the likelihood of serious harm as compared to other options should be accepted, as long as the basic needs of the child are secured. This family's decision was to keep this child alive and without a doubt they were caring for him in the most loving way.

We had a third encounter; now I was in the pediatric intensive care unit (ICU). He had gone through one long hospital admission since our last encounter, and I had become interested in the concepts behind end-of-life care decisions. I came to realize that difference in opinion when dealing with end-of-life discussions is common, if not expected, and this can be exacerbated by cultural, religious, or socioeconomic diversity. Again, the parents remembered me and I did remember them too. His parents, especially his father, had drifted away from Catholicism. He had now turned to alter-native therapies: alkaline water, therapy with magnets, numerology, and positive thinking. According to this new way of thinking, accepting the diagnosis of his son would enhance tumor growth. It was a new challenge and I was pre-pared, or so I thought.

I wanted to understand their level of awareness of their son's current situation. The father said he knows that 'the thing,' referring to the tumor, is there but he knew his son's immune system will recover and heal his brain completely. We had a conversation to set goals for this specific hospitalization. They wanted him to be able to go home in the same state he was a week ago, breathing on room air via his tracheostomy tube and feeding via nasogastric tube. These were reasonable goals, I said, but we needed to fulfill the following criteria for him to go home: he needs to be off the ventilator or tolerate minimal ventilator settings, he needs to come off of pressors, and we had to bring his sodium down. He had a new diagnosis of diabetes insipidus, likely related to his brain tumor. Many individuals have a positive illusion that good things are more likely to happen to them and therefore initial goals are set with this background belief. These parents believed that their son would fully recover to become his previous self. Not being able to achieve highly valued goals causes significant distress in a family and of-ten in the medical team. Engaging in new achievable goals can reduce the feeling of failure. Miller et al define the term 'regoaling' as the process of setting new goals, once the initial goals, such as complete recovery, are no longer realistic.² They emphasize that hope is crucial in this process; proposing that high hope individuals experience less negative and more positive emotions when they are unable to achieve a goal, allowing them to engage more easily in the process of setting a new goal like limiting interventions or signing a do not resuscitate (DNR) order. I was about to embark on my first 'regoaling' experience with this family.

Within a few days we successfully achieved the goal of bringing the sodium down to normal values. I informed the family, but I also told them that we were far from reaching the other two goals. He slowly and steadily decompensated, to the point where he depended of the ventilator and intra-venous drugs to live. "What is the next step" they asked, getting ready to engage to a new goal. We set a family meeting to discuss a brain function evaluation called 'brain-death protocol'. You could see the parents grow anxious with the proposal, but they were curious about the idea of proving that their son's brain was working, as they believed. The meeting went well, they stated they felt respected, and recognized that the team was doing everything to care for their son. Then we got to the point of explaining the evaluation. We disclosed that in New York State, as in most of the states, if a patient is diagnosed brain-dead he is legally dead. The

father initially responded with anger. "Let's say he is diagnosed brain-dead, which he is not. What would you do next? Do we have a say? Can I take him home? Can we have a second opinion?" We responded to all these questions, which seemed to calm him down. The father had read, in a hand out provided by our palliative care team about our hospital's protocol, that an electroencephalogram (EEG) could read his brain waves the same way an electrocardiogram (EKG) reads heart electrical activity. This was attractive to him, as he had heard and read stories about people in a coma with brain activity captured by EEG who woke up years later. He agreed to the evaluation, only if an EEG was included. We arranged to perform the protocol the next morning. The entire team waited anxiously around the patient, I started a timer, and we started the protocol. It was evident that he didn't have any breathing effort. He met all the criteria and was pronounced dead.

The family had requested time to arrange for the funeral before we disconnected him. We encouraged them to involve the sisters and family members who had not been to visit lately. That night, the entire family gathered around him as his parents dictated the next step. They wanted him to breathe room air, so we slowly decreased the oxygen content to 21%. Then they requested to slowly turn down the vasopressor. Once we reached 0 mcg/min the father started talking out loud to his family and all of us who were in the room. "You will see his heart will beat on its own." The family, hopeful, looked at the monitor. To my surprise, the blood pressure remained stable and even a little hypertensive during the first minutes, but then it gradually became profoundly hypotensive and his heart rate decreased until it stopped. Family members screamed and video-called relatives. His sister led a prayer with smart and beautiful words, which we joined. The father saw me across the room. I extended my hand which he ignored. He hugged me whispering, "You and your team are true professionals. Thank you for caring for my son."

References:

1. Ross LF. Children, Families, and Health Care Decision-Making. New York: Oxford University Press, 1998.
2. Hil DL, Miller V, Walter JK, et al. Regoaling: A conceptual model of how parents of children with serious illness change medical care goals. *BMC Palliat Care*. 2014. doi:10.1186/1472-684X-13-9