



# 🔍 EMPATHY AND THE DIVIDE BETWEEN MEDICAL AND PATIENT/FAMILY WORLDVIEWS

*Sebastián Proaño*

A lack of empathy while standing in as a translator for another physician's patient and family raised the following question: can one be culturally insensitive to one's own culture? The following narrative explores how the divide between medical and patient/family worldviews can deleteriously affect one's cultural sensitivity.

## INTRODUCTION

Loss of equilibrium was the symptom that led to a diagnosis that changed the life of this teenager and his family forever. It was also how I felt reflecting on my role in providing their medical care. I first met the family the day the young man was diagnosed; a colleague resident asked me to translate a conversation for her that included words such as: tumor, urgent, intensive care, brain. The parents emigrated from South America 14 years ago, at the time of their son's birth. He was now being diagnosed with diffuse intrinsic pontine glioma. I translated that he had a 'tumor cerebral' and he required close monitoring in an intensive care unit; he was at risk of deterioration. The eyes of the parents staring back at me following my explanation were those one gets when someone is speaking in a foreign 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 the conversation between another physician and his patient and had my own patients on my mind. But at home, I ran the episode over in my mind, and then over again; I thought about how I was asked to 'drop a bomb' on a patient that wasn't mine. Could I have spent more time empathizing with the family? After all, they were from the same country that I was from. The biggest question in my mind became this: was I being culturally insensitive towards my own culture?

Months later, I became a second-year pediatrics resident, and along with this title came the responsibility of being the overnight resident in the Emergency Department. We received a notification by EMS: "We are coming with a 14-year-old in septic shock, ETA

7 minutes.” The patient had a respiratory rate of 10 breaths per minute, maybe even less. His forehead was warm and covered with perspiration. We connected him to the monitor; his blood pressure was below 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 head 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. The mother sat in the corner, surprisingly calm. Once I started the interview, I realized that he recognized me from our first encounter. Only later did I realize how important I had been 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 hopping from one hospital to another. The main reason for this ‘hospital tourism’ was that doctors considered palliative care with minimal invasive interventions in his best interest, an idea the parents refused completely. They were convinced 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. I felt they were not respecting their child’s autonomy.

Autonomy is one of the hardest concepts to define in pediatrics. To whom does it belong? Most children lack the abilities required for a person to make an autonomous decision [1]; therefore, the roll falls to a surrogate decision maker—most often the parents. Undoubtedly, autonomy is a moral norm of high priority in medical ethics. [2,3] While Western bioethicists such as Ross have advocated for concepts such as family autonomy, particularly in pediatric ethics [4], some cultures have historically differed from the Western concept of individual autonomy in that they consider the family as the smallest unit for moral considerations. [5,6] 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 their child alive, to my eyes, caring for him in a loving way.

We had a third encounter; now I was in the pediatric 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 differences in opinion when dealing with end-of-life discussions are common, if not expected, and this can be exacerbated by cultural, religious, or socioeconomic diversity. [7] Again, the parents

remembered me; I remembered them too.

His parents, especially his father, had drifted away from Catholicism. He had now turned to alternative therapies: alkaline water, therapy with magnets, numerology, and positive thinking. According to his new way of thinking, accepting the diagnosis that his son had a brain tumor would enhance the tumor’s growth. Parents of dying

children have different types of coping mechanisms. Latino-American families, in particular, adhere strongly to faith and religious practices. [8] It is widely-shared belief that Western medicine is the first-line approach to treat children with cancer, but people from many cultures will rely on complementary and alternative medicine to increase the likelihood of cancer remission and restore general health. [9] I never asked why the parents drifted away from their religion, but I assume the results they were looking for were not being delivered by their faith nor western medicine. Sometimes parents feel better when they do something, giving themselves some sense of agency in a situation where they otherwise have little control.

I wanted to gauge the level of understanding of their son’s current situation. The father said he knows that “the thing,” (referring to the tumor) is there, but he believed his son’s immune system would recover and heal his brain completely. How do you respond to such a statement? Certainly, I was never trained for this. Should I nod to portray empathy? Should I voice my scientific thoughts? The thoughts in my mind were clear: Do not antagonize, but do not encourage unrealistic expectations.

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 room

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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 would need to be off the ventilator, or tolerate minimal ventilator settings, he would need to come off of vasopressors, and we would have to bring his sodium down. He also

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. [10,11] These parents believed that their son would fully recover and return to being his previous self. Not being able to achieve highly valued goals causes significant distress in a family, and often in the medical team. [6] Engaging in new achievable goals can reduce the feeling of failure. Miller et al. define *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 such as limiting interventions or signing a DNR order. I was about to embark on my first *regoaling* experience with this family.

Before I did so, I worked with the team to address the criteria necessary to bring the child, JB, home. Within a few days, we successfully brought JB's sodium down to normal values. I informed the family, but I also told them that we were far from meeting the other two criteria.

He slowly and steadily decompensated, to the point where he depended on the ventilator and intravenous drugs to live. "What is the next step?" they asked, getting ready to engage to a new objective. We set a family meeting to discuss a brain function evaluation called Brain-death Protocol. I could see the parents grow anxious with the proposal, but they were curious about the idea of proving their son's brain was working, as they believed it was. The meeting went well; they stated they felt respected, and recognized the team was doing everything they could to care for their son.

Then we got to the point of explaining the evaluation, and informed them that in New York State, as in most states, if a patient is diagnosed brain-dead he is legally dead. The father initially responded angrily, "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. JB's father had read a handout provided by our palliative care team about our hospital's protocol. It noted an EEG could read brain waves the same way an EKG reads heart electrical activity. This was attractive to him, as he had heard and read stories about people in comas with brain activity captured by EEG who woke up years later. He agreed to the evaluation, but only if an EEG was included. We arranged to perform the protocol the next morning. The entire team waited anxiously around the patient. I set a timer, and we started the protocol. It was evident he did not have any breathing effort. He met all the brain death criteria, and was pronounced dead.

The family requested time to arrange for the funeral before we disconnected him. We encouraged them to involve his 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%. They then requested we slowly turn down the vasopressor. Once we reached 0 mcg/min JB's father started speaking out loud to his family and all of us in the room, saying, "You will see his heart will beat on its own." The family looked hopefully at the monitor.

To my surprise, the blood pressure remained stable, 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."

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THE AUTHOR HAS DISCLOSED NO CONFLICTS  
OF INTEREST

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*Continued next page.*

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*Continued from: "Medical Complexity Induced Foster Care: My Rapunzel" page 18*

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