Right Brain: How to treat the untreatable

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Mr. X came in to the hospital late at night. He initially had left-sided weakness and headache but rapidly progressed to decreased level of consciousness (Glasgow Coma Scale score was 4). From home, I reviewed his head CT, which revealed a large supratentorial bleed that had ruptured into both lateral ventricles, and significant midline shift. Without having seen the patient, I already knew that his prognosis for survival was very low.

I met some of Mr. X's family in the morning; several of his children were present, though his wife was not. They did not ask many questions, but they understood the severity of the situation. As the family was Hmong, and Mrs. X did not speak any English, the children reported information back to her. I gave them a graphic description of the best-case scenario—that Mr. X would be severely disabled, living in a nursing home, certainly with hemiplegia but likely with speaking difficulty and comprehension problems as well. I also quoted the prognosis from an intracerebral hemorrhage score study¹ and told them that only 3% of patients in his situation survived after 30 days.

The next day I learned that the family's plan was to consult a shaman. Our team thought that the intention was to perform some sort of farewell ritual for Mr. X prior to withdrawing care for him, similar to other religions performing last rites. However, in my reading, I learned that traditional Hmong spiritual practice has a very different perspective.^{2,3} The shaman's role was not to say goodbye; rather, the shaman's role was to heal Mr. X. Traditionally, a Hmong shaman must plead with the spirits of the deceased elders to extend the preordained lifespan by burning "spirit paper." When it became clear that this was the family's intention, we deferred further discussion about goals of care and gave them time to do whatever they felt was needed. We suspected that the shaman would tell them that he would not live, and that the family would soon choose comfort care.

By the end of several days in the intensive care unit, the patient's neurologic status, which was poor, had stabilized—not worsening, not improving. His other critical care issues were stable, and our team believed that this patient would not likely die from his neurologic insult directly, though the medical issues were still potential threats. Interestingly, the same day, we heard back

from the family regarding the shaman's advice. He had told the family that the previous day would have been an auspicious day to die; however, since Mr. X had not passed away, he would now be able to survive. Their sources and ours seemed in agreement at that point.

Unfortunately, the shaman's prediction proved to be premature. In spite of maximal medical therapy, Mr. X's neurologic status declined. As he approached brain death day by day, I tried to communicate with the family as best as I could. We arranged numerous family meetings and conversations by phone. Despite our coordinated efforts to communicate, the message seemed to be lost in translation. Mrs. X was absolutely certain that her husband was comatose not because of the large bleed in his head, the severe hypertension, or the methamphetamine abuse, but rather, because the spirit of Mr. X's brother was attacking him for a perceived slight. From her perspective, the doctors, and all their interventions, seemed to be incidental to the primary "treatment": resolution of the spiritual dispute between Mr. X and his brother. If the dispute were resolved, Mrs. X expected her husband to completely—and immediately—recover.

I was very conflicted while caring for Mr. X. I believed that we were performing painful interventions on him frequently, with no real chance of achieving the goals that the family desired. Even though I explained many times to the family that he would not be able to fully recover, they always deferred to Mrs. X, who in turn took her advice exclusively from the shaman. I asked the family several times to consider comfort care as an alternative method of treating him, because I had lost hope that we were helping him—as did our various attendings and the critical care team helping us. Despite these talks, Mrs. X firmly demanded "everything" be done to keep him alive. She also revealed her greatest fear: if we abandoned him, his spirit would torment her children, much as his brother was tormenting him.

Mr. X continued to decline very slowly but steadily over the next 2 weeks, first showing a "blown" pupil on one side, and later both sides. His neurologic examination started with purposeful movements on his unaffected side, and gradually progressed to bilateral extensor posturing. I knew that there are some patients who do survive Mr. X's initial presentation; in fact, one of my

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continuity clinic patients was living proof. Nevertheless, it seemed clear to me that at some point, Mr. X lost the chance to be a survivor. Since he could not survive, I wanted to stop hurting him. Although I directly told this to the family, they felt that the facts of the case were outside my understanding altogether, and disregarded my predictions.

The alliance between doctor and patient is typically predicated on the idea that the doctors have special knowledge and skills, and the patient (or representative) trusts the doctor to guide the patient toward health and away from disease. When the patient or family's belief system is based entirely outside of the structure the physician is working in, what is the role of the physician? Should we have said "Trust us, we know what we are doing?" If so, we would have to claim greater levels of predictive powers than we truly possessed: sometimes the "hopeless" patients do recover, like my clinic patient. Should we have said, "We trust you, tell us what to do?" If so, we would have to claim less knowledge and skill than the amount we are entrusted with to begin with as physicians. In the end, we walked an imaginary middle road where we did what we would do if he were going to survive, and regularly offered comfort care measures as an alternative option. Was that the right approach? It provided the family with some autonomy, and it gave him the best "chance" at surviving that we knew how to give. And yet, it felt somehow wrong, or unfair. If we, the medical team, believed that Mr. X would recover, then we should not have repeatedly offered comfort care measures. On the other hand, if we thought medical treatment was futile, we should not have offered it at all. Because we thought he would die, but were not completely certain of this, we performed this strange procedure of treating him while asking for permission to stop doing so.

In the end, Mr. X did die. His death weighs upon me more than others like him. It is hard enough that our job often places us in the impossible position of fighting death itself. For Mr. X, the challenge was amplified because his wife believed that a fully healthy man lay before her, waiting for a family dispute to be resolved. It was my desire to offer him a death free of suffering given that I could not assist in restoring his

life. My desire was met with a resistance I had not encountered before, not because the family did not understand, but because the family was not interested in our understanding. At the same time, our role in not "abandoning" him in order to protect his children seemed more important than whatever medical issues we thought we were treating. In effect, our job was to provide spiritual elixir for the children.

There is a degree of cultural sensitivity required of physicians. Sometimes it means that we need to respect a family's wishes for special death rituals before withdrawing care; other times it means that we need to recognize that withdrawal is not permissible due to religious beliefs. In this case, withdrawal was possible, but only under circumstances governed by a spirit world that we were not privy to.

The small function that a physician can perform while caring for a terminally ill patient is being present and helping the patient and family come to terms with the situation. We were excluded from that entirely, because the family's belief nullified our role. Did we help him? Did we help the family? Did we perform medically reasonable acts? I still do not know.

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Dr. Goldenholz takes full responsibility for the data, the analyses and interpretation, and the conduct of the research; the author has full access to all of the data; and the author has the right to publish any and all data separate and apart from any sponsor.

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DISCLOSURE

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