HEALING ARTS

Materia Medica

Communication with the Uncommunicable: Proceedings of the Ethics Committee

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"[My] only job is to be an impartial witness... that is, to know how to distinguish important testimony from unimportant, to place my characters in the proper light and speak their language."

Anton Chekhov (1860–1904)

INTRODUCTORY REMARKS BY THE CHAIR OF THE HOSPITAL ETHICS COMMITTEE

This is a special session of the Ethics Committee to consider the situation of Mr. R, a patient in the surgical intensive care unit (ICU). Mr. R is no longer able to make medical decisions for himself, and Mrs. R has decision-making authority under the Family Health Care Decisions Act of New York. However, because of the complexity of the situation and the differing views on how to proceed, we thought we should meet today. The medical student on the team caring for Mr. R will present the case.

PRESENTATION OF THE CASE BY THE MEDICAL STUDENT

Mr. R is a 32-year-old man who was brought to the emergency department (ED) yesterday after suffering a seizure in a shopping mall. When the emergency medical technicians (EMTs) reached Mr. R, they saw that he had a contusion on the right side of his head. Mr. R regained partial consciousness about 10–15 minutes after his seizure and told the EMTs that

he did not want to go to the hospital, because it was against his religion. He asked to be taken home, where the elders of his church would care for him.

Despite Mr. R's objections—Mr. R's consciousness seemed to wax and wane, and it may not have been clear what Mr. R's wishes really were—the EMTs started an intravenous (IV) line and brought him to the hospital. In the ED, Mr. R resisted treatment. He told the staff to call his brother, who is an elder in the church, to come and take him home. He was restrained so he could not pull out the IV. The ED staff was not able to contact Mr. R's brother initially.

About 20 minutes after arrival in the ED, Mr. R became drowsy, vomited, and had a grand mal seizure, which left him difficult to arouse. An emergency MRI showed a small subdural hematoma and also a well-demarcated mass of the left temporal area, which was thought to be a meningioma. Mr. R was admitted to the ICU about 24 hours ago. Since then, he has become progressively less responsive and unable to communicate. A repeat MRI today shows that the subdural hematoma is larger.

Mr. and Mrs. R have an eight-year-old boy and a five-year-old girl.

TESTIMONY OF MRS. R

Please forgive me if I seem a little nervous. I am so upset about this. This happened so suddenly. Fred had gone to get something at the mall and the next thing I knew the doctor at the hospital called me and said Fred had a seizure and was there in the emergency department. He had been having some headaches lately and his brother and the others in the church were praying with him. Fred thought the headaches were getting better. That is our way. We don't believe in going to doctors. I appreciate how everyone here has been so kind and wanting to help Fred. The doctors and nurses in the emergency room and now in the ICU have been very nice. But this is strange to us. I think that we should go home and let the people in our church take care of him. I don't know. I just want Fred to get better. I'm so worried. Our children know their daddy is very sick. They want him to get better. What I would do, or what they would do, if something happened to their father?

Author's Note: I was inspired to write this by the death of the 11-year-old daughter of faith-healing parents due to diabetic ketoacidosis, the short story In a Bamboo Grove by Ryunosuke Akutagawa (1892–1927) in which different versions of the truth appear, including testimony from a murdered man through a medium, and the observation that a patient in a vegetative state responded yes or no to questions during a functional magnetic resonance imaging study,** raising the possibility that some people deemed dead may communicate with us. The latter I take to be a contemporary application of Akutagawa's communication through a medium. Although this currently may be somewhat fanciful, simple yes-no communication can lead to more complex communication, such as when Jean-Dominique Bauby, a man with locked-in syndrome who communicated by blinking his eyes, created The Diving Bell and the Butterfly (Vintage Books, 1997).*

* <http://www.cbsnews.com/stories/2009/10/06/national/main5367848.shtml>

** Monti MM et al. Willful modulation of brain activity in disorders of consciousness. *N Engl J Med* 2010;362:579-89.

Published online July 8, 2011

J Gen Intern Med 27(1):129–31

DOI: 10.1007/s11606-011-1792-8

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Did my husband express his thoughts about end of life matters? Oh, no. We never talked about that. I know that Fred is not afraid to die. Neither of us is. We both have faith in God. What happens is God's will. We have faith that everything works out for the best.

TESTIMONY OF MR. R'S BROTHER

In addition to being Fred's brother, I also am an elder in our church. I mean no disrespect, but we believe in a healing God and to go to doctors is disrespectful of His power. If we go to the doctor, we are putting the doctor before God. If God wants us to live or die or to suffer or to be happy, that is His will. It is our custom in our church to meet frequently and pray for each other. Over the past month, since Fred's headaches started, several of us have been praying with him every day. The headaches are getting better. I appreciate that you are trying to help Fred, but he should come home now. Staying here is an affront to God's will. We want him to come home. We will take care of him.

Does Fred believe the same as I do? Yes, he does. He has been a faithful member of our church since he was a boy. He is a part of our faith community. Since he began having the headaches, he has met and prayed with us. Yes, he doesn't want to be here. He wants to be home with us.

TESTIMONY OF THE ATTENDING NEUROSURGEON

You have heard about the subdural hematoma and the probable meningioma. Mr. R's clinical condition is deteriorating rapidly and that is due to the expanding subdural. We have an acute situation here and he needs surgery today. I cannot be more forthright. He has an acute problem—the subdural—which we can remove surgically. He also has an underlying tumor in his brain, which appears to be a meningioma. This probably caused the seizure, which resulted in him falling and striking his head and developing the subdural hematoma. Meningiomas typically are benign and can be cured by surgery. So surgery now is necessary to treat Mr. R's immediate, acute problem as well as the underlying tumor.

What will happen if we don't operate? If he leaves the hospital now? Well, that is pretty clear. The subdural hematoma will continue to expand, he won't wake up, and he probably will die. It is certain that the meningioma will not go away. It is absolutely the wrong thing to do.

TESTIMONY OF THE ICU NURSE

I have taken care of Mr. R most of the time since he has been in the ICU. He has never been what you would call alert, but he seemed cooperative before he became really obtunded. When he could talk, he asked me to pray with him. He was worried about his family. When his kids came last night, he knew them and was so glad to see them. I know he doesn't want to die. And the nurses are trying so hard. You know, we see some

pretty sick people. Many don't have much of a chance to make it. But here, if we can just get him to the operating room and evacuate the hematoma and excise the meningioma, there's a really good chance Mr. R can go back to his family and be normal.

TESTIMONY OF MR. R'S SISTER

There's something you should know. I don't believe the way my brother believes. I grew up in that church, but I saw that it wasn't for me, so I left. We've drifted apart. I have to admit the relationship is a little strained. I came today because I heard my brother was here and I want him to stay here and be treated for his medical problems. This is what he needs, not going home for prayer treatment. I got worried last week when I called him at the holidays. He told me about the headaches. He said they were getting better and everyone was praying for him, but he kept talking about the headaches. I don't think they were getting better. Now this happened. He needs the operation. I believe in modern medicine. I believe that God works through modern medicine, and we should use it. If Fred goes home and they pray for him, he won't get better. And the kids, they need him. If he goes home and dies, that's not God's will.

TESTIMONY OF THE HOSPITAL CHAPLAIN

I met Mr. R shortly after he came up to the ICU. We didn't have much time to get acquainted, especially since he was a little confused at first and then hasn't been able to communicate at all. He did say something about wanting to go home. I also spoke with Fred's brother, and I know something about their church. They are a very close family of believers, very supportive of each other. They believe in the power of God to cure illness or the will of God to do otherwise. There is a term you use on this committee—autonomy. That describes the right every person has to make a decision for him or herself providing the person has the mental capacity to make such a decision, the relevant information, and understands the consequences. Autonomy is something we value very much in this society. We don't want other people to tell us what to do, especially if it goes against our values and beliefs. Even though many of us would not agree with sending Mr. R home and in the care of his church, I think we need to take this into account. I mean, we need to ask, 'Is this what Mr. R would want?' I know this goes against the grain of what most of us think is right for ourselves, but do we have the right to force Mr. R to do something he would not want to do?

TESTIMONY OF MR. R USING FUNCTIONAL MAGNETIC RESONANCE IMAGING TECHNOLOGY

When the headaches started, they weren't so bad. After a few days, I told Nancy and then George. When the headaches didn't go away, we all prayed. I told George and the others the headaches seemed to be getting better. I wanted them to get

better. But, you know, I don't think they got much better. What could I do? I felt I had to say they were getting better. Always we had relied on God's will when we got sick, even when the kids got sick. We always got better.

Nancy asked me if I wanted to see a doctor. I knew it wasn't the right thing to do but I was tempted. When I had the seizure at the mall I was really scared. But when the EMTs got to me, I told them I didn't want to go to the hospital because, well, to be honest, I thought I had not had enough faith, or maybe this was God's will. I didn't know what to do. I know I didn't want to die and leave Nancy and the kids.

Then this morning, when the doctors saw me on their rounds, I heard them talking about the need for surgery and what might happen if I did not have it. After they left, I heard God's voice. He said, "I am with you always. I will never abandon you." I felt so much better. I knew I had made the right decision.

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