Jeffrey Spike, "The Sound of Chains: A Tragedy," *The Journal of Clinical Ethics* 16, no. 3 (Fall 2005): 212-7.

The Sound of Chains: A Tragedy

Jeffrey Spike

Jeffrey Spike, PhD, is an Associate Professor in the Department of Medical Humanities and Social Sciences at Florida State University College of Medicine in Tallahassee, *jeffrey.spike@med.fsu.edu.*

THE CASE

This is a case I will never forget. I think it was so clear from the beginning that it involved nothing but misery that no one else on the Ethics Consultation Service wanted to get involved. It fell to me because I was the director of the service. I didn't realize it at the time, but this contributed eventually to the haunting aura of the case: it was one of those few cases that I had no choice but to perform; I couldn't say no. Looking back, each of those cases (there were a few others, but never more than one a year) is especially memorable, as if the forces that put me into those situations and held me there added to the intensity of the experience.

It was an anomalous case from the beginning. The request came from social work, which is not strange in and of itself. Most of our requests came from a resident or attending physician, but social work was the next most common source of requests.

It was the nature of the request that was unusual, rather than its source: should the mother of a patient be allowed to visit her child? Of course, the question was followed by further details: the child was a shaken baby, and the mother was a suspect in the crime. From my phone conversation, I inferred that many people on the team felt the answer should be "No."

My gut reaction was that a mother should be allowed to visit her child unless we have solid evidence that it will endanger the child. And unfortunately the harm was already done. Furthermore, even if the mother was the one who had harmed the child, it was most likely due to a momentary loss of control — terrible yes, culpable yes, inexcusable yes, but unlikely to happen again, especially when interacting in a controlled and supervised environment.

But I try never to give my first "gut" reaction over the phone. Even when I know it is a well-justified opinion, and a slew of articles come to mind that could serve as references for the eventual consult note, I didn't know enough of the individual circumstances to know if the references or paradigms influencing my opinion were truly appropriate to the case.

After talking to the social worker, the situation was more complex and confusing than I first realized: the mother and her boyfriend said they were both home with the baby the evening the baby was injured, and each said that they hadn't done anything to the baby, and neither had the other person. One was the perpetrator, and the other was willing to defend the perpetrator. And they were acting as each other's alibi. They both were most likely lying, but no amount of effort by the police helped to coax either one to confess. Logically, it was an example of the prisoner's dilemma, a well-known paradox that philosophers learn in graduate school. Each person will receive the lightest sentence if they can rely on the other to not confess.[1]

As with any consult, I went to see the patient so I could establish my own opinion, rather than basing it on the reports of others. The baby's name was "Angel," a name that only made the story sadder, with its intimation of a spiritual being that lives in a better, less violent world. And, adding to the poignancy, Angel indeed looked peaceful, lying there.[2] His eyes were closed, and he looked like he was sleeping. He had no marks on him, not a scar, not a bruise, nothing. He had beautiful color and the fat cheeks of a healthy, well-fed baby. In my memory — clearly false — he was smiling.

But Angel was still ventilator-dependent and in a coma after two weeks, and the neurological prognosis was that either the coma would be permanent or the coma would lighten, and Angel would emerge into a persistent vegetative state (PVS). Some neurologists use the phrase "awake but unaware" to describe PVS. Having seen adults in a PVS, I knew that many people would find that an even worse outcome: the baby would remain unaware (according to the best neurological science), but everyone involved in the baby's care would be plagued by doubts (and even nightmares) about whether the baby was suffering. Most people, when asked, think it would be better not to "wake up" in that case; they consider PVS to be a fate worse than death.

When I went back up to the unit the next day, I realized that my initial intuition about the staff wanting to prevent the mother from seeing her baby was correct. Whatever reticence I heard over the phone from the head social worker I had spoken to was not present in the bedside staff, who were clearly angry. Some of the nurses on the pediatric intensive care unit (PICU) team were very attached to this beautiful little baby, and they were so outraged at the mother that they did not think she should be allowed to visit. It was impossible to tell how much that was to punish the mother and how much it was to protect the baby. But I think the two motivations were inseparably mixed together in the emotional swirl. Those who would even consider it as an option did so only in the hope that it would make the mother confess to what had happened.

Furthermore, as the prognosis began to sink in and be accepted, there was a feeling among many members of the team that the mother should let her baby die in peace, with the loving nursing staff by his side. Perhaps in an effort to protect the baby, the nurses saw themselves playing a maternal role — a kind of maternalism — which may be a relic of the traditional professional role in nursing, much like paternalism in medicine. Preliminary reports from the jail, where the mother was being held, were that she refused to withdraw life-sustaining treatment. That only further angered the staff, who saw this as prolonging Angel's suffering or prolonging his dying, rather than prolonging his life.

Of course there were legal twists that made the whole case seem to have the logic of *Catch-22*. If the mother allowed her baby to die, then the charge would become murder. So, to put it mildly, she did not have any incentive to make that decision. Even the best of parents have trouble "letting go" of children. But, in this situation, the mother had already lost her child, and any confession would mean that she would go to jail, or her boyfriend would, or both.

If ultimately the mother refused to withdraw life support, then Angel needed to be placed in a long-term care facility for the rest of his life. At the time, there were no long-term care ventilator beds for children in town. Let me clarify; I do not mean that the beds were filled, so none were available, but that there were no beds for that level of care for children in the whole 14-county metropolitan area. The social workers in the hospital knew this, of course, but this was not why they felt it would be better to stop the ventilator. Nor was it primarily an issue of financial cost to society. Had Angel's mother been someone who would be able and interested in visiting him regularly, I believe they still would have felt it would be somehow cruel or inhuman to keep him alive. My impression is that this is a widely held opinion in the population at large. From what I have heard over the years, I speculate that this option is based on two independent feelings (and I choose that word deliberately): first, there may be some neurological *hubris* in the received view that such patients cannot be aware of anything, and that if the experts might be wrong about this state, then such a life (in what is more akin to the "locked-in" state) would be so terrible that no one would wish to live that way; and, second, whether the patient is aware of it or not, the resulting life is really not a human life, and is so undignified that no one would want their body preserved and treated by strangers in such a way, for a protracted period of time, when there is no hope of recovery.

The staff was still divided on whether the mother should be allowed to visit, the reason for the initial call. The nurses who were willing to let the mother visit also wanted me to be there, with the hope that I could persuade her to stop the life-sustaining treatment, not to increase the severity of the legal charge, but for the sake of the baby. But what could I say to persuade the mother to withdraw life-sustaining treatment? According to the best neurological knowledge, Angel was not suffering. The people most likely to suffer in cases of patients in a PVS are the caregivers.

I wrote a short note and also explained to the social worker (a very experienced and skilled pediatric social worker) that I felt the mother should be allowed to visit, and that I would be willing to be there at the time, if that's what the doctor and the staff wanted. This short handwritten note did not provide justifications (that would be saved for the final note, typewritten and researched), but my sense was that even if the mother was responsible for the injury, she no doubt deeply regretted it now, and there was no reason to further punish her by not allowing her to see her child. That it also meant her seeing the consequences of the act could not be a reason to prevent her from seeing the baby; if anything, it would be better for her to make a decision based on a full understanding of the situation and the consequences of the decision.

Once an ethics consultation is called, it is standard procedure for the ethics consultant to join family meetings. There are many reasons for this. First, the family should have a chance to meet and talk with every person involved in the process. Imagine the distrust ethics could engender if it were somehow kept secret or appeared to be "behind the scenes." Second, it is often the case that the ethics consultant can aid the communication by making explicit some things that the medical experts take for granted but members of the family don't know. It is not unusual for me to go to a meeting unsure of whether I can add anything valuable, only to find later that I contributed an insight that would have been overlooked, and that afterwards leads people there to thank me for my participation. The lesson is that there is no way to know *a priori* if my presence will be needed, and hence it should be done as a matter of routine process. But I also cautioned the staff that they should not expect me to be able to change the mother's mind, although I thought it would be right for someone on the team to discuss the baby's prognosis with the mother when she visited.

In such cases, what I might be able to add is assurance for the parent that the decision to stop life-sustaining medical treatment is among the reasonable options, ethically and legally, and that others have made that choice and had it respected in similar circumstances. But even when that topic is presented fairly to parents who have their baby's best interest at heart, it can be hard for them to know what to do. Many of the clinicians involved in this case, however, hoped that perhaps actually seeing what Angel was going through would make his mother more willing to make the ethically best decision and "let go."

I never should be the one to describe the prognosis. I am always careful to tell patients that I am a PhD and not an MD, and that I am not there to give them any medical information or advice. But I may be able to clarify some things for them, and even when I cannot answer their questions, I may be able to help them ask the right questions of their doctors. In this case, as I typically do, I had spoken to the attending by phone to make sure I understood all of the essential clinical information in advance. He assured me that the injury was devastating and irreversible. I told him that I would be at the meeting being planned for a few days hence. I assumed that he would be at the meeting as well. When I arrived, the meeting seemed already to have begun. A nurse, the social worker, the mother, and two police escorts were crowded into the small room, and all spoke in hushed whispers. But I was surprised as I looked around the still room: there was no doctor in the group. The mother was by Angel's bedside, with the nurse on one side of her and one of the police on the other.

The mother was dressed in the orange jumpsuit of the local prison. I had not thought about what she would look like, and the prison uniform surprised me. However, much more disturbing was that she was in chains. One heavy chain connected to metal bands around her ankles, presumably so she could not run. A second heavy chain connected to metal bands around her wrists. And a third connected the two chains together, so she couldn't raise her arms much above her waist. Indeed, either due to their short length, or their weight, or the weight of her guilt, she could barely move. A slow shuffle was all I ever saw, and whenever she moved there was a sound of heavy chains.

I at first felt like an intruder because everyone was standing up, close together, and facing the bed. But when I introduced myself, I quickly sensed that everyone there had been waiting for me. The mother had tears in her eyes, and was talking to her baby. At that moment, my feeling was just of overwhelming tragedy, not anger.

The baby's mother mumbled something so quietly I couldn't hear her. But there seemed to be some discussion of what she had said, and then the social worker turned to me as if to ask what I thought. I had to ask what she had said, and the social worker explained to me that the mother wanted to hold her baby. I didn't think this was a bioethical issue, yet I often have admonished other ethics consultants not to avoid difficult issues by saying it wasn't a bioethical issue. All too often an issue can be seen in different ways, and will only be handled fairly if everyone is willing to acknowledge that they have a legitimate role in helping to resolve it. Otherwise too much authority will settle into the hands of one person who is willing to take control. Ethicists are there to help balance the equation, if nothing else. And to deny this woman her request seemed punitive, all the more so because there was no way to know if she would ever see her baby again. So I spoke up, and said I thought she should be allowed to hold her baby, even though (I added) I didn't really think that decision was mine to make.

To my surprise, after some whispers between the two police guards, one took out a key and unlocked the prisoner's handcuffs. The social worker helped pick up Angel and put him in his mother's arms, and she sat down in the rocking chair that is in every PICU room and held him. She talked to him, and no doubt hoped for some kind of a response. But she got none. There was still no doctor there, and it only then gradually began to dawn on me that nobody was waiting for a doctor to show up. The meeting had begun, those there had been waiting for me to show up, and now this was "my meeting" to run.

I was becoming more aware of the continual sense of surprise this case presented, as it did not follow the usual rules. I felt that I had been unexpectedly conferred with more of the role of an agent in the drama and less of an adjudicator than I typically assume, and this too contributed to the haunting quality that the case has, in retrospect. No one had ever suggested to me that this would be my meeting to run, or, if they had, it was in language so polite and veiled that I had missed it entirely. While I had run meetings before, it was more common for me to attend meetings that were run by either a social worker or an attending. And I most certainly never ran a meeting that in effect was both the first and last chance to discuss a grim prognosis, as it is called in the medical world.

I had to think on my feet, carefully choosing each word that needed to be said almost simultaneously with saying them, internally deliberating so as not to exceed the limits of what I was capable of saying. I wanted to be accurate, and not coerce the mother into a decision, but I also did not want to pull any punches. This was not a case in which there would be other chances to have the information sink in, or for her to return with more questions. By now nearly a month had passed since the injury, and not a single note in the chart indicated any hope of meaningful recovery. I told her that, and explained just what the alternatives were: stop the ventilator and let Angel die in his sleep, or continue his life indefinitely in a nursing home once one could be found that would take a baby. I told her that while the decision was hers to make at that point, many people, including many of the people at the hospital who were taking care of her baby, felt that the kindest and most respectful thing to do would be to let Angel die in peace. I added that I had known other parents that had made that choice, and no one condemned them for it; in fact, they had received understanding and empathy for their difficult decision. But, I also admitted, I had known other parents who chose to not stop life-sustaining treatment, and although their babies never improved, were never able to walk or talk or even to sit up or respond to their mother's voice, no one could condemn the parents for that decision either.

She listened to me but said nothing. After what felt like too short a time, the guards indicated that her time was up. She placed Angel back in his bed and thanked me, and said she needed time to think about the alternatives. That was the last time I saw her.

CONCLUSIONS

As expected, Angel's mother did not choose to stop his life support. In this story, the mysteries were never solved. I don't think we will ever know who committed this horrible crime, and I think that contributes to its unforgettable quality.

Many people who hear of this case wonder why the mother was even considered a valid surrogate decision maker for her child. And there are things that many people would say only in private: paying for this level of care for years or even decades is a terrible strain on society. In a country where paying taxes is often resented, and good institutions are subject to continual cutbacks, many people who can gain a lot from small services will suffer due to a single costly case like this one. One often senses that people who call for an ethics consult are expecting miracles: to rectify all the injustice, or at least to call to task all of the people who created it. These unanswered questions and unspoken doubts contributed to the palpable sense of anger toward the mother and dissatisfaction toward the ethics consult that I felt from the many good and well-meaning people who were involved in this case.

There are other cases that haunt me. But as I sort them out, I see that most of them haunt me because of a lack of support or even opposition from sources that one would have hoped to be allies of clinical ethics. But that is more disillusionment with one's department of health, or attorney general, or hospital counsel. It is not caused by the case *per se,* which could have been handled more humanely, had only others listened to good advice and put the patient's interests ahead of their own legal fears, financial interests, personal needs, political agenda, or religious beliefs. But more haunting is this case of Angel, which nothing could have helped to improve. Some might want to call this a sense of futility, but that word is overused in bioethics, with far too many different meanings. It is not the futility of the treatment that is haunting, if indeed that term is appropriately applied here.[3]

Instead of futility, I prefer to consider this case to be an example of the true meaning of a tragedy. In many of my other cases, I knew there was no good alternative, but there was a "least worst" choice, and it was my place to explain or even occasionally try to persuade everyone that that choice was the best of the alternatives open to us, even if it was not a happy decision to have to make.[4] But in Angel's case, there was no consolation and no redemption to be found for anyone.

NOTES

1. For example, see the discussion in R.M. Sainsbury, "The Prisoner's Dilemma," in *Paradoxes,* 2nd ed. (Cambridge, U.K.: Cambridge University Press, 1995), 66-71; or N. Rescher, *Paradoxes: Their Roots, Range, and Resolution* (Peru, Ill.: Open Court Press, 2001).

2. I have used the baby's real name because this case was public, not just from being in the court system but also reported in the newspaper. And his name adds to the poignancy and haunting quality of the case.

3. On the topic of futility, I have often surmised that futility is in the eyes of the beholder. Continuing life-sustaining medical treatment might keep Angel alive for decades, especially if he emerged to a PVS and was no longer ventilator dependent. See "Persistent Vegetative State," in *The Encyclopedia of Science, Technology, and Ethics* (New York: MacMillan Press, 2005).

4. A good example of the consultant and persuasion is a case of a patient with a recent traumatic injury who refuses treatment. I do not believe coercion should be allowed, but do think some degree of time to consider the alternatives might be imposed, while one satisfies one's own concerns that the patient's decision is fully informed. See J. Spike, "Controlled NHDP for a Fully Conscious Person: When Death Is Intended as an End in Itself and It Has Its Own End," *The Journal of Clinical Ethics* 11, no. 1 (Spring 2000): 73-7; and J. Spike, "Author's Response: The Limits of Persuasion," *The Journal of Clinical Ethics* 11, no. 1 (Spring 2000): 92-3.