

# Too close for comfort?

## *A family physician questions whether medical professionals should be excluded from their loved ones' care*

Michael C. Klein, MD

**Y**ou be the husband and let me be the doctor." How many times have I heard this refrain? My usual response, spoken out loud or muttered under my breath, is "Right, if you'd be the doctor, I could be the husband." Where does the idea come from of completely dissociating the role of family member from that of physician family member? What is so improper about a physician being involved in the care of a loved one? Is it the potential for a clouding of judgement? No argument there: judgement is clouded, perspective is lost. But the issue is not that simple. What about the family doctor who is the only physician or one of a small number of doctors in a small town? What about emergency situations? Is the information provided by a physician family member necessarily wrong, distorted, suspect? Should it not be considered on its own merits?

How do responsible medical staff deal with the involved physician family member? Do they seek information? Do they invite him or her to be present at rounds? Do they allow or encourage the physician family member to see the patient's chart? Do they report investigations and lab results in general terms or provide the specific numerical results, or do they exclude the physician family member from the loop? What is the difference between giving feedback to a nonmedical family member in terms that he or she can understand and providing more technical feedback to a family member with a medical background? Isn't it just a question of providing information at the correct level for the specific recipient?

### A case

My wife Bonnie is in the ICU, where she will spend many weeks quadriplegic, on a respirator and "locked in." Her nasoduodenal tube repeatedly becomes dislodged, either by accident or because she unconsciously pulls it out, and sometimes hours go by before it is reinserted. She is getting her fluids, calories and medications by that route. House staff are busy. It's a low priority. Some of the house staff are not very adept at the task and inadvertently cause my wife great distress. Do I let them practice until they get it right? Do I wait? No, at times I slip it in myself. Some nurses are scandalized; others are pleased and encourage my intervention. Some house staff think I'm a lunatic, others ask to be taught.

Bonnie is slipping into respiratory failure because, it will later be discovered, of a mass impinging on the respiratory centre in her brain stem. It's the weekend. I am alone with a first-year family medicine resident who is also covering the neurology service and is doing his best with her and me. Bonnie's neurologist is on vacation. The covering neurologist, from a nearby hospital, never comes in to see her. I am sleepless, have no energy left and am giving up, certain that I will lose her. The resident perseveres and, working with the attending physician, mobilizes the various subspecialists for a consultation. Many think that Bonnie will die anyhow, although each blames a different disease. One neurologist thinks that she has a fulminant malignant lesion that is migrating in the brain stem. Another thinks that it is a rapidly destructive form of multiple sclerosis and recommends a



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cytotoxic drug, which is given. The immunologist thinks that it is a severe form of autoimmune vasculitis and recommends plasmapheresis and high doses of steroids, which are given.

This postulation of multiple and concurrent illnesses violates everything I have ever been taught. I don't understand why the problem cannot be, as originally thought, a bleed in the brain stem, a diagnosis that would tie it all together — but an MRI scan, which would settle the matter, is not recommended by the radiologist. MRI is a scarce resource. And what would be the point anyhow, the hypothesized location being surgically unapproachable? I am looking for a single, fixable lesion, as originally suspected by Bonnie's neurologist. I push for the MRI scan. My specialist colleagues feel that I am over-involved and unrealistic but reluctantly agree, probably to get me off their backs.

We are about to take the ambulance to another centre for the MRI scan. I ask the ambulance attendant about the method he will use to suction the tracheostomy. He states that he has an electric vacuum suction device. I ask, "What happens if it fails?" He replies, "It never fails." Suspicious type that I am and a firm believer in the many versions of Murphy's Law, I ask him to wait while I run up to the delivery suite to get a few DeLee oral suction traps just in case. During the trip the suction machine fails. I use the oral device until we arrive at the hospital.

We are about to enter the MRI chamber. The respiratory technician who came with us has, for reasons I will never understand, returned to our hospital. Perhaps she thought that this hospital would supply respiratory support. I am bagging my wife by hand while local politics fail to be sorted out. The MRI technician says that the test cannot be done; the patient is moving too much and ventilation by bag and mask has never been done during an MRI because the metal parts cannot be used within the magnetic field. Fortunately, Bonnie is breathing shallowly on her own through the tracheostomy and requires only intermittent ventilatory support. I implore the technician to let me ventilate her between MRI cycles while he stabilizes her from the other end of the tube. Reluctantly he agrees. Holding her steady for 1½ hours, the technician obtains an acceptable study and is pleased with his efforts, so stiff from the ordeal that he can hardly stand.

The MRI scan clearly shows the lesion. I am alone, staring at the view box, awaiting transport back to our hos-

pital. I am an amateur, but to me it looks vascular, encapsulated, benign and in a very bad place. Consensus is that the lesion is inoperable. What's to lose? Bonnie is dying and will likely have another bleed. She has already had two. I arrange for copies of the MRI scan to be sent to neurologist friends and colleagues across North America. They help locate a surgeon in another Canadian city who has been practising on dogs and has been awaiting the appearance of the right patient. We are told that no surgeon has been that low in the brain stem before: patients usually die from respiratory failure before a surgeon gets to them. Bonnie is taken by air ambulance. Even though there is space on the aircraft, I am prohibited from accompanying her and assisting with her care. "It is not done," I am told. I follow with my daughter many hours later on a commercial jet, not knowing if Bonnie is still alive.

Bonnie is in the ICU on a respirator and her tracheostomy needs frequent suctioning. To do this, the respirator needs to be disconnected, and Bonnie needs to be ventilated by hand while the cleaning takes place. I am comfortable with the equipment. One nurse asks me to leave, saying that she cannot do her work with me there. Two others integrate me into the care, never questioning who is in charge: they are. Some

nurses realize that working with me not only makes their job easier but is therapeutic for me.

The surgery is successful. A huge brain-stem malformation is removed. It has bled several times and has wiped out most of one side of the medulla and part of the pons, destroying the nuclei of cranial nerves 9 through 12 on one side. Bonnie can't swallow and one vocal cord is paralyzed. In any case, she can't talk because of the tracheostomy. I am able to communicate with her using a letter board and a complex system of eye blinks and, eventually, by lip reading. Some of the staff want to learn how to communicate with her; some don't.

Bonnie is having panic attacks, feeling that she can't breathe. Some doctors and nurses think she is "spoiled." "What's her problem? We saved her life." Some nurses can talk her down to some extent from the attacks. Others don't try. They think I am indulging her by breathing her down and reassuring her, empathizing with her paralyzed and powerless state.

One nurse, equally comfortable with the technical side of the job, wants to learn how to manage panic attacks. Staffing levels provide for excellent one-to-one nursing, but some nurses are comfortable with caring for Bonnie

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## Why should physicians check their training and experience at the door when a close family member gets sick?

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and some are not. Why, I wonder, should those who are not be forced to care for her? I work with the charge nurse to create a roster of nurses who want to do the job.

I suggest a pharmacologic approach to the panic attacks. The anesthesia staff who run the ICU are uncomfortable and ask for a psychiatry consult for Bonnie — or for me; I'll never know. The psychiatrist acknowledges that he has not been in an ICU since medical school and asks me what I would do. I propose the same benzodiazapine and antidepressant combination that I would use in an office setting. Together we discuss the approach with the ICU staff, and a plan is organized. It helps. The nurses who want to care for Bonnie ask me to give them a session on panic attacks. We organize it with the charge nurse. Care dramatically improves, and the nurses take pride in their accomplishment.

### Common themes

During the more than 6 months in 3 hospitals, I found Bonnie's care less than optimal on many occasions. The medical and nursing staff varied in their response to these discoveries. At times they were grateful for my intervention and responded with corrective measures. On other occasions some were angry and suggested that I was over-involved and meddlesome. What I found most fascinating was that the staff who could deal with me were the best at their jobs, not only at the technical and diagnostic level but at the human level as well.

My experience only seems particularly strange because I am a doctor. What about family members who are not physicians? Are their ideas less valid? Are they less entitled to contest a dysfunctional system? I don't know if, as a physician, I had more or less difficulty in obtaining optimal care for my wife than a layperson might have had. Probably both. Considering my experiences, it is disturbing to consider how a nonphysician family member could have dealt with the situation.

The irony is that anyone who has worked in an institution knows that mistakes are inevitable. People and machines are fallible, and in the end we need all the help we can get. Family members, physicians or not, need to be integrated into the care of a loved one. Their ideas must not be trivialized, their concerns demeaned. They, along with the professional staff, will have the best interests of the patient in mind.

Professionals need to work with the situation as it is. Information, from whatever source, needs to be weighed, taken seriously and put into context. Why should medical professionals check their training and experience at the door when a close family member gets sick?

So what is the problem? I think it is fear, fear that we as professionals will be found wanting, that we might be discovered to be not quite on top of the case. It is difficult for some of us to say "I don't know," to appear as less than omniscient. Diagnostic and therapeutic ambiguity, although a normal part of medical practice, may be more difficult to acknowledge to a fellow professional. Or perhaps the problem is the deeply held belief, impressed upon generations of physicians, that it is medically correct to exclude physician family members from the care process. This view needs re-evaluation.

I am much more concerned about my family than about the feelings of professional staff. Yet I have a responsibility to express my concerns in the most helpful way possible. How to be vigilant but not overbearing? It's a difficult question. I'm open to suggestions.?

Dr. Klein's wife, Bonnie Sherr Klein, is an award-winning filmmaker and writer. She tells her story in *Slow Dance: A Story of Stroke, Love and Disability*, to be published by Knopf Canada early this year. Bonnie functions autonomously and continues to improve 9 years after her stroke.

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