

## Virtual Mentor

American Medical Association Journal of Ethics  
June 2008, Volume 10, Number 6: 360-364.

### CLINICAL CASE

#### Family-Centered Decision Making

Commentary by Muriel Gillick, MD

“Let’s pause here,” said Dr. Lawrence during morning rounds. “This is Mrs. Burke’s room. She’s a 78-year-old woman who came in for a knee replacement 4 months ago and was re-admitted a month later with fever, weakness, and *Staph. aureus* bacteremia. She continues to have bacteremia. We have done a complete work-up multiple times, but we’ve yet to find the source of her infection. She’s been back to the OR twice on the recommendations of the infectious diseases consultants, but the orthopedic surgeons have stated this is not coming from her knee. Mrs. Burke has also had imaging of her spine and knee five times, an echo of her heart three times, and almost daily blood cultures. She has been on several antibiotics, all based on susceptibilities. Today we will have our fourth family meeting. Mrs. Burke’s daughter is very expressive of her own wishes and requests, which lately do not seem to be correlating with her mother’s, and we have found that regular family meetings help to keep everyone on the same page.”

After he finished his report, Dr. Lawrence led the team into Mrs. Burke’s room, and Mrs. Burke asked about the day’s plan. “Are you going to poke and prod me again or will I finally get a little peace?” Dr. Lawrence replied that her anemia, a possible side effect from the antibiotics, was slightly worse and that Mrs. Burke had the option of waiting until tomorrow to recheck her blood counts or receive a blood transfusion that day in the hope of making her feel better.

Mrs. Burke replied, “Dr. Lawrence, I’m so tired of everything. I don’t want the transfusion. I want to be left alone for a while. I really just want to go home.”

Later that morning during the family meeting, Mrs. Cominsky—Mrs. Burke’s daughter—said, “We want everything possible done to locate the source of my mother’s infection so that we can eradicate it. If that means more labs, running more tests, getting more fluid samples, doing more MRIs and echoes, don’t hold back! I want my mother to get well.”

Dr. Lawrence looked at Mrs. Burke, who sat quietly by her daughter’s side. “Is this what you want?” he asked.

“Of course that’s what she wants!” Her daughter exclaimed. “She wants to get better!”

“Well, we had a discussion earlier today, and your mother indicated that she was not interested in undergoing more tests. She has been here for several months now, and, understandably, she is tired. Her preferences—and you can correct me if I misunderstood you, Mrs. Burke—are to hold off on further testing right now and to possibly... .”

“My mother is sick! She is not clear-headed! Of course, she wants everything done!” interrupted Mrs. Cominsky.

Dr. Lawrence asked Mrs. Burke to state her preferences so that everyone knew what she wanted, but Mrs. Burke simply shrugged her shoulders and replied in a defeated tone, “My daughter takes care of me at home. She knows what’s best.”

### **Commentary**

Frustrated by his inability to find a source for Mrs. Burke’s fever and convinced that she is dying, Dr. Lawrence is ready to accept her statement, “I really just want to go home,” as an indication of her wish to limit treatment. Her daughter, Mrs. Cominsky, asserts confidently that her mother may be tired but that her goal is “to get better.” In truth, neither goal is realistically achievable, and the emotions swirling through the clinician-patient-daughter triad may be preventing a productive discussion of how best to approach Mrs. Burke’s care.

*Mrs. Burke’s goals.* Mrs. Burke’s wish to just “go home,” articulated when she is weak and febrile after months of illness, needs to be further explored. Does she mean “home” literally, or is “home” a euphemism for dying? If home is taken at face value, Mrs. Burke needs to understand that she would most likely require 24-hour care, preferably with hospice services. If Mrs. Burke does understand that “going home” would be going home to die, or if in fact her words mean “going home to heaven,” she should be assessed to determine whether her wish stems from severe depression or from a judicious assessment of her condition.

*Mrs. Burke’s daughter’s goal.* Although Dr. Lawrence may have come to the conclusion that all reversible causes of fever have been ruled out, he and the house staff have probably continued to report even the small fluctuations in blood cell counts or the results of the latest set of blood cultures to the family. But this may not have been presented in relation to Mrs. Burke’s overall health state. Precisely because no single, terminal illness has been identified and the cause of the recurrent fevers remains elusive, the medical team may never have explained to Mrs. Cominsky that her mother is dying. Anthropological studies of hospital care have demonstrated that the clinical staff’s shift from trying to improve a patient’s condition to acknowledging her dying typically takes place only shortly before death [1].

*Family-centered decision making.* The physicians seem to experience Mrs. Cominsky as aggressive and overbearing. They see her as riding roughshod over her mother’s wishes, and they regard themselves as defenders of Mrs. Burke’s

autonomy. Physicians often interpret the behavior of family members as disruptive or even dysfunctional, particularly in the acute care setting when the patient is seriously ill [2]. It is difficult for the team to appreciate that Mrs. Burke's daughter has been her primary caregiver, that she knows her mother better than any one on the medical team, and that the two may well have shared values. Dr. Lawrence needs to move from seeing Mrs. Cominsky as an adversary to viewing her as an ally.

The intensely individualistic model of Western biomedical ethics contributes to the tendency to regard family as problematic and an impediment to care. Physicians are taught to focus on the needs of patients in isolation from their families or communities even though patients almost always function in a social context. Frail older individuals seldom make decisions without the input of those closest to them, and they are rarely in a position to implement their decisions without the help of others.

Older, sick patients typically want their families to be involved in medical decision making. Sometimes, as when Mrs. Burke says "my daughter takes care of me at home; she knows what's best," they are eager to transfer authority to a surrogate, even if they are cognitively able to make their own decisions. In a classic study of community-dwelling older patients, the vast majority expected their families to make decisions for them and regarded this as a form of extended autonomy [3]. Even though family caregivers often find their responsibilities burdensome—suffering financial strain, experiencing resentment and guilt, and sacrificing their own health for their loved one [4]—they often also enjoy profound satisfaction from that role [5].

Cultural factors may also shape patients' preferences for the locus of decision making. We are not told anything about Mrs. Burke's ethnic background, but in many cultures, particularly among Asian Americans, patients do not wish to be told their prognoses and defer decision making to a spouse or adult child [6]. Physicians must be sensitive to this possibility and ask patients what role they wish their families to play [7].

### **The Emotional Overlay and its Consequences**

The readiness of Mrs. Burke's physicians to accept her statement about wanting to go home as a wish for comfort-oriented care is a reflection of their dedication to supporting her autonomy, but also of their own emotional state. Caring for an older person who suffers one complication after another, with little prospect for recovery to her baseline level of function, is draining for the medical team. They question their competence; they wonder what they have missed and whether their resources would be better used elsewhere. Mrs. Cominsky's strident tone leads them to worry they will be sued if the outcome is death.

These factors contribute to feelings of anger, resentment, and inadequacy, which are common in physicians who care for seriously ill patients. Unfortunately, these emotions can also adversely affect patient care, leading physicians to avoid the

patient or family, to make dismissive comments about the family to other doctors, and to further impair already strained lines of communication. An article by Meier and colleagues describes the cascade of behaviors generated by physician emotions and argues that the medical team should name the feelings they are experiencing, accept them as normal, reflect on their emotions and possible consequences, and seek peer support [8].

### **Resolution**

When Dr. Lawrence and the medical team sit down to talk about next steps with the patient, Mrs. Cominsky, and (ideally) other involved family members, they should begin by acknowledging that it is a difficult time for Mrs. Burke and her family. They may also want to acknowledge that seeing her do poorly is hard for them, too. Saying “I wish medicine had the power to turn things around” can go a long way toward creating a badly needed alliance among the stakeholders in this drama [9].

Having said that things are not going well, the team needs to explicitly address Mrs. Burke’s prognosis. They should be prepared to explain that, even without a single, unifying terminal diagnosis, older patients often succumb to the combined burden of multiple comorbidities [10]. They also should take seriously the implicit concern raised by Mrs. Cominsky that her mother’s discouragement at her lack of progress is getting in the way of sound decision making. One way to demonstrate an understanding of Mrs. Cominsky’s concern is to evaluate Mrs. Burke for depression. By acknowledging Mrs. Cominsky’s sensitivity to her mother’s mood, they are implicitly legitimizing her participation in discussions about her mother’s medical care. They should accept that decision making is familial rather than exclusively patient-centered and explore cultural and ethnic factors if appropriate.

At the same time, the physicians would do well to discuss their sense of frustration with their colleagues. Seeking a second opinion from a geriatrician (not just from the infectious disease specialists or orthopedists who are apt to focus on a single organ system rather than on the whole patient) may confirm that shifting from care focused on life-prolongation to care focused on comfort is appropriate at this juncture.

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