

Virtual Mentor

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CLINICAL CASE

Miracle Surgery for Foreign Patients

Commentary by Reza Yassari, MD, MS

Dr. Jackson is an accomplished neurosurgeon at a large academic health center. He is approached by a colleague on behalf of a patient who recently came to the United States from Guatemala with her twin sons who are joined at the head. Image studies are encouraging about the survival of both infants, but they will need intensive hospital care for many months after the surgery. Further predictions about their long-term functioning and capabilities cannot be made at present.

Dr. Jackson's department is interested in performing this ground-breaking surgery. He and other surgeons have offered to perform the surgery without pay, and the hospital has agreed to provide post-operative inpatient care at no expense to the family. Funding for care after the twins leave the ICU and for outpatient follow-up has not been secured, and the family cannot pay for it privately. In Dr. Jackson's judgment, the sooner the surgery is done the better the boys' chances for recovery. He must decide whether to proceed with the initial surgery even though long-term care is not assured.

Commentary

This case poses two fundamental questions: First, should the family's ability to afford long-term—perhaps even life-long—care for these children play a role in the physician's medical decision making about whether to perform the surgery? And second, would the answer change depending on the patient's immigration status or country of origin?

In considering question one, it is helpful to know that patients with devastating neurological diseases are treated every day. Many need extensive post-operative care and medical management associated with a high rate of complications. A great number have some degree of neurological sequelae that require long-term care. The physician's role is to be actively engaged in helping the patient's family understand the disease, the treatment options, and the prognosis, while preparing caregivers for the possible outcomes and conveying realistic expectations for long-term care. The role of the medical staff is to act as patient advocates and facilitate the best possible outcome. Securing funding, however, can be a more difficult, but related, task. Unfortunately, under the U.S. health financing system, few people have the financial means to guarantee payment for long-term care, and most would face dire financial hardships in the event of a devastating medical problem.

Even when a patient has adequate insurance at the time of an acute medical problem, there is no guarantee that coverage will be available perpetually; financial situations change, insurance can be revoked or terminated, and caretakers who give up their jobs to care for sick parents, children, or spouses lose their benefits. Is it then acceptable to consider the patient's economic situation—even partly—as a factor in the medical decision making process? Should we refuse to do surgery because the patient will probably not be able to afford this extensive care? Would it be permissible to refuse performing surgery with only a 1 percent risk of a potentially devastating outcome, unless the patient could demonstrate secured funding for long-term care? What about a 20 percent complication rate? In other words, at what point does a surgeon decide that the probability of unaffordable or financially crippling follow-up care overrides the benefit that the surgery is likely to confer, and is there such a point at all?

Most people are not able to comprehend immediately and fully the emotional and economic consequences of a devastating illness. It is the duty of physicians and the medical staff to support and guide the family toward understanding the ramifications and then the possible solutions to the expected implications of the disease. This process should include discussion of the likelihood of long-term care and its cost. The physician has an ethical duty to do his best to create solutions for both the immediate and long term. That said, does the physician undermine his commitment to nonmaleficence if he proceeds with surgery without securing funding for all the steps of the surgery and postoperative care? Some might argue that if no funds are available for future care, the surgery sets the patients on a path that could harm them (and their family), because with suboptimal care, the outcome will be suboptimal. I would argue that, if the immediate medical or surgical intervention helps the patient, refraining from that treatment because of economic reason poses a far graver violation of the physician's duty to do no harm.

Financial and economic considerations should not be an obstacle to immediate medical treatment for an acute problem, be it an appendectomy or the separation of craniopagus. Likewise, the medical decision-making process for the long-term care of the patient has to be done outside the constraints of the patient's immediate financial restrictions. Not all solutions will be immediately available, nor should it be a requirement that they be. Sometimes solutions only become perceivable during the search.

The situation of the conjoined twins is better than that of the average uninsured patient; at least the immediate costs are covered. The funding for the perioperative and immediate postoperative care is available, and the surgical team has donated their services. The surgeon, Dr. Jackson, believes that delaying the surgery puts the twins at a higher risk. Some would argue, then, that delaying the surgery because funding for long-term care has not been secured is negligent.

Is the Offer Purely Charitable?

There is an aspect of this case that is hinted at in the scenario that must be examined. The donation of time and resources by the hospital and the surgical team may seem purely altruistic at first glance, but the procedure is likely to attract a lot of media attention. The institution will be in the national and maybe international news, the doctors will give press conferences, and all of their colleagues will be waiting to read the case report when it is published. The reputations of both the hospital and the surgeon could benefit. Might these factors influence the decision to operate and, if they do, is that ethically acceptable? The ideal way to avoid this potential conflict of interest is to maintain anonymity. After all, the purest form of philanthropy is anonymous charity. But the number of personnel involved and the accessibility to media in the electronic age make the ideal impossible to achieve.

If one were to accept the fact of media attention, it might become a solution for securing long-term care. The hospital could forgo all publicity except for that which is of direct benefit to the patient and use the media to help secure the necessary funding. In high profile cases, physicians are under intense scrutiny, and duty to their patient's well-being must be adhered to even more stringently, although one hopes that a high standard of personal responsibility is always set by the physician, independent of whether the case attracts media attention or not.

My answer, then, to the first question is that, where surgery can benefit the patient, a surgeon need not wait for all funding to be in place, although he or she has a duty to inform the patient of the likely need for follow-up care and its costs and to help the care team assist the patient in securing the funds.

Treating Non-Citizens

The second question remains: do physicians have the same responsibilities when treating foreign nationals without immigration status in the U.S. or people traveling to the U.S. for medical care? Should these "medical tourists" be required to provide proof of sufficient medical coverage before undergoing treatment? Foreigners who would like to study in the U.S., for example, have to document secured funding for their studies when applying to universities and for immigration purposes. The U.S. health care system has a difficult time providing adequate services to a large portion of its own population. Is it permissible, then, to expend our limited resources on those who are not U.S. citizens and live in other countries when they cannot afford their own care? Should the hospital concentrate on allocating its resources to American citizens, the population for which they are most responsible? Would it be ethically acceptable to limit care to foreign nationals with insurance or otherwise secured funding? Who is responsible for the cost of the postoperative and long-term care for those without secure funding, in the U.S. and when they return to their country of origin?

If the principles of beneficence and nonmaleficence have any merit, then, in accordance with Kant's categorical imperative, they should be "universal laws," i.e., they should apply regardless of gender, race, culture, political affiliation, and legal

status. The U.S. health system cannot and should not do everything for everyone, but the limitations should be established within the frameworks of U.S. legal structures and be consistent with the principle of distributive justice. The resources of the hospital are valuable, and the decision to offer major surgery without compensation must be made with a clear understanding of the economic circumstances of the institution and full consent of the administrative and medical staff. Once there has been a commitment to care for a patients, the institution should seek to provide the best long-term and follow-up care for the patients, especially if it cannot be obtained in their home country. In the case of the twins and other high-profile cases, there may be secondary gain for the hospital and the physician. Hence the hospital may have a moral obligation to allow patients to use its infrastructures to secure long-term care while the patients are in the U.S.

Nevertheless, the twins will eventually return to Guatemala, to their little rural village and to an underdeveloped health care system. Who will provide for their future care? If one or both of the twins had a shunt placed to treat drainage of the cerebrospinal fluid, who will assist them if there is a malfunction? The absence of infrastructure in countries like Guatemala where basic sanitary and health care provisions are nonexistent is the real problem here. Medical missions abroad by U.S. physicians put band-aids on this global disparity, but do not address the underlying causes of the infrastructure inadequacy.

Ultimately, the answer is the development of educational programs for the training of physicians, nurses, and medical personnel in countries that currently lack adequate health system infrastructures. One could train people in the U.S. with the commitment that they will return to their home countries. Another approach is to develop educational programs that are mutually beneficial for students and trainees alike. The Virtue Foundation, in collaboration with its partners, has developed a program to train local doctors and nurses in some of the least developed nations of the world, such as Burundi. Integrating a rotation of physicians and other health care workers and support staff to continually teach the local personnel during their stay helps build the necessary infrastructure and knowledge that creates sustainable development. This arrangement allows the visiting physicians from the U.S. and other developed nations to gain experience abroad while teaching and assisting local physicians. With continual coverage throughout the year provided by these rotations, a “mini-residency program” is created that allows the local physicians and nurses to learn and adapt their new knowledge to the realities on the ground and perpetuate this replicable and scaleable model.

These longer-term solutions do not help our twins, but I do believe that Dr. Jackson should not limit their care because they are not U.S. citizens. All possible venues should be explored to use the existing resources in Guatemala, as inadequate as they may be, to give the twins the best possible long-term care, including a possible return to the U.S. for follow-up if necessary.

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