

# Should Foreigners Get Costly Lifesaving Treatments in the United States?

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Many foreign parents bring their children to the United States for medical treatments that are unavailable in their own country. Often, however, parents cannot afford expensive treatments. Doctors and hospitals then face a dilemma. Is it ethically permissible to consider the patient's citizenship and ability to pay? In this Ethics Rounds, we present a case in which a child from another country needs an expensive treatment. His parents cannot afford the treatment. He has come to a public hospital in the United States. We present responses from experts in pediatrics, bioethics, and health policy.

Many foreign parents bring their children to the United States for medical treatments that are unavailable in their own country. Sometimes, these are affluent patients who can pay cash for their treatments. Often, however, parents cannot afford expensive treatments. Doctors and hospitals then face a dilemma. Do we have an obligation to provide medical care only on the basis of medical need, or is it ethically permissible to consider the patient's citizenship and ability to pay?

The clinician may not perceive a conflict. For millennia, medical ethics has exhorted physicians not to consider the patient's ability to pay but only to consider the patient's medical needs. By this view, the clinician should always advocate for medically indicated treatment.

Hospital administrators may have a different perspective. Administrators have a duty to maximize the utility of available resources, especially in a publicly financed hospital. How should they balance the appeal of the 1 child against competing needs? And what should be the role of a hospital ethics committee?

In this Ethics Rounds, we present a case in which a child from another country needs an expensive treatment. His parents cannot afford the treatment. He has come to a public hospital in the United States. How should the doctors, the hospital, and the ethics committee respond to this common dilemma?

## CASE PRESENTATION

A 10-year-old Eastern European boy has recurrent and refractory acute lymphocytic leukemia (ALL). His previous treatments include multiple rounds of chemotherapy. Unfortunately, these treatments have been unsuccessful, and the boy has now exhausted all options that are available in his country. Without additional treatment, the boy will die of his disease.

In searching for possible life-extending therapies, the boy's parents identify a US children's hospital with an active program in hematopoietic cell transplantation (HCT) for cases of relapsed ALL. At the time, HCT was the standard of care in the United States for relapsed ALL (this case occurred before the widespread use of chimeric

## abstract

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antigen receptor T-cell therapy, although the issues raised would be similar for the newer therapy). The reported survival rate was 15% to 50%, depending on how quickly the disease relapsed in a child after initial therapy. HCT is also highly resource intensive, with an average length of admission of >30 days and an average cost in the hundreds of thousands of dollars.

The boy's parents raise funds through their local community and travel to the US children's hospital where he is given an appointment to be seen by a pediatric oncologist. The oncologist confirms the diagnosis of refractory ALL and agrees that the patient needs HCT.

The amount of funds raised by the parents is insufficient for HCT. The family does not have health insurance. Given the family's available resources, the hospital would not be fully compensated for this patient's care. In addition, this facility is a not-for-profit facility that serves as the only children's hospital in a large, geographic, multistate region. Its primary mission is to serve children of this region. The facility receives taxpayer-funded subsidies to do so.

Should the hospital agree to perform HCT on this patient? If not, what is the appropriate alternative option?

**Shane Wo, MD, and Abby Rosenberg, MD, MS, MA, Comment**

This case represents a familiar conflict between bedside-level patient needs and institutional-level community needs. In other words, how does one prioritize immediate fiduciary obligations to the individual patient versus current and future obligations to the greater community? Put another way, how should we prioritize bedside- versus institutional-level needs? In this case, offering HCT has implications for both.

At a bedside level, offering HCT appears appropriate. Saying "yes" without some degree of required financial reimbursement is in the patient's best interest; he will receive a potentially lifesaving therapy regardless of his family's ability to pay (for the sake of argument, we will assume that the benefit from this potential cure outweighs the harm from potential treatment toxicities). Saying "yes" also seems to respect the duties of the medical team. Having developed a professional relationship with the boy, medical providers may feel obligated to continue to provide the best available medical care, including HCT. Lastly, saying "yes" seems intuitively to align with the ethical principle of justice. If another child in the community with refractory leukemia would be offered HCT, why should this child not be offered the same?

Unfortunately, saying "yes" without a financial requirement is much more complicated when this case is evaluated on an institutional level. First, offering HCT is likely not in the best interest of the hospital, regional community, or larger pediatric community. The estimated average cost for pediatric allogeneic HCT and the subsequent 100 days of care exceeds \$300 000.<sup>1</sup> If the hospital absorbs these costs, it will decrease its pool of funds for uncompensated care of the local community. In addition, offering HCT may deplete limited resources, such as medical personnel, equipment, and bed space, again potentially making them unavailable for local community needs. Taken together, saying "yes" may compromise the hospital's ability to achieve its primary mission of serving the local pediatric community.

Secondly, justice-based arguments are rarely limited to the bedside level; the consequences of decisions and sustainable, fair allocation of resources must also be considered. An uncompensated HCT, for example,

sets an untenable precedent. Should other children be offered HCT free of charge? Should other international patients receive similar resource-intensive care without sufficient payment? What happens if the hospital becomes overburdened with volume and other uncompensated care? Offering HCT without adequate compensation will lead to unsustainable consequences and further undermine the hospital's preexisting promise to the local community.

We acknowledge that withholding HCT may feel inherently wrong for the bedside clinicians, especially because it means this patient will certainly die of his leukemia. Tragic situations, such as this one, present a difficult choice and a conflict of commitments that cannot be easily or even satisfactorily resolved. When resources are limited, some patients will not have their medical needs met. This is an age-old predicament in medicine; in settings of scarce resources, the benefit of 1 patient may correspond to additional suffering for another.<sup>2</sup> Our responsibility is to choose the lesser of 2 evils, and this is often the option that provides the greatest overall good.

With the conflict of bedside versus institutional priorities in mind, how does one proceed with this case? Although providing expensive therapies to all is humanistic, it is not realistic. Instead, we contend that HCT should not be offered to this patient until his family is able to pay the estimated cost of care. This recommendation is founded on the utilitarian argument of maximizing total benefits.

The use of a utilitarian argument is not without precedence and often serves as the basis for decision-making in cases that involve the allocation of scarce medical resources.<sup>3</sup> For example, recent consensus guidelines for allocating scarce chemotherapies for children

with cancer rely on modified utilitarian models, which both maximize total benefits and also respect system- and patient-level constraints.<sup>4</sup> Recommendations are used to prioritize total pediatric lives and suggest clear, a priori institutional guidelines for decision-making and rationing such that patients, families, and health care staff know what to do in such cases.

It should be noted that in these guidelines, all children at a hospital are assumed to be otherwise similar with respect to community citizenship and geography. The present case is therefore somewhat distinct. Moreover, geography matters. Distance from specialty medical care is a known factor of health disparities; for example, in kidney transplant cases, greater distance is associated with greater mortality, leading to calls for wider access to subspecialty care in the United States.<sup>5</sup> In this case, however, the hospital has made a promise to the local community that has supported it and relied on its services. This promise must be kept.

An additional distinction with our recommendation is that we assume that HCT has not already been offered to this patient. If a provider, as a representative of the institution, has already given a bedside-level promise of HCT, then this promise also must be fulfilled and HCT pursued.

Moving forward, we recommend that hospitals establish clear and transparent institutional policies regarding requirements for care. These policies must be readily available not only to patients and families but also to hospital staff. Families will know what is expected of them, and staff will be familiar with the constraints placed on what they can offer to patients. Hopefully, the number of cases like this one will be fewer. However, when cases such as this one arise despite established policies, staff should stabilize and meet the immediate needs of a

patient and also be prepared, when needed, to compassionately not offer HCT. Additional steps may be considered on a case-by-case basis, including referrals to other accepting hospitals or, tragically, to discharge from the hospital.

#### **Emily A. Largent, JD, PhD, RN, Comments**

This is a heartbreaking case because treatment for the boy exists, but access to it does not, and the consequence is his certain death. Nevertheless, declining to provide HCT is permissible and, I would say, necessary under the circumstances.

US hospitals offer technology and expertise considered too expensive or too specialized to be widely available outside of the United States. Thus, as is the case here, many patients with high-acuity illnesses wish to come to the United States to receive care for conditions considered difficult to treat or even untreatable in their own country. In many instances, these are affluent patients who represent a lucrative market for US hospitals because they usually pay (in cash) at a higher rate than that set for Medicare, Medicaid, or private insurers. In other cases, insurance will cover their care. Still, other international patients receive charitable care that is paid for by a humanitarian organization.<sup>6</sup> International patients, such as the boy at the center of this case (ie, those who are neither affluent, insured, nor sponsored), face a nearly insurmountable obstacle to receiving care.

Of course, many American children also encounter significant financial barriers to receiving care. In 2017, there were 4 million uninsured children in the United States,<sup>7</sup> and many millions more were underinsured<sup>8</sup> (recent political events have threatened insurance for even more children<sup>9</sup>). These uninsured and underinsured children are at a greater risk for delayed

care, unmet health care needs, and poor health outcomes than their adequately insured peers. When uninsured and underinsured children receive hospital-based care, it is often subsidized by federal and state taxpayer dollars and funds generated by the hospital's other patient care activities. To be eligible for such financial assistance, it is often necessary to establish US citizenship or designated legal status, state residency, and low-income or limited financial assets.

Our existing system, as just described, is characterized by gross inequities intra- and internationally, and the status quo is unacceptable. The solution to the larger problem of access to care for children (universal coverage domestically and meaningful contributions to child health globally) is necessarily a political one and one for which we must fight. However, the narrower problem in this case is how to permissibly ration care within the existing system.

Ideally, international patients and their families will be screened by the hospital before they travel so that they know what treatments are available to them and whether they can access them. A troubling aspect of this case is that the boy and his parents have already traveled a considerable distance, but despite being at the children's hospital, HCT remains a far-off possibility. As a result of this feature of the case, simply not telling a prospective patient that he cannot receive care is more akin to ending a treatment relationship. The patient should not simply be abandoned, which would violate a central tenant of medical ethics.<sup>10</sup> What, then, should be done?

In other cases, there may be means to cobble together free or reduced-price care, such as pharmaceutical Patient Assistance Programs, but that is neither feasible nor desirable here. In HCT, costs related to hospitalization, such as medical staff, room and

board, laboratory, radiology, and blood products, are the major drivers of overall costs.<sup>11</sup> The children's hospital may have some funds available for the uncompensated care of international patients (these would be distinct from funds disbursed through the hospital's financial assistance policy, which is shaped by state and federal community benefit requirements entailed by nonprofit hospitals' tax-exempt status<sup>12</sup>). Yet, it would be preferable for the children's hospital to use those funds so as to maximize health benefits rather than to offer expensive HCT, with its 15% to 50% survival rate, to 1 child and exhaust what uncompensated care the hospital may be able to offer to international patients for years to come.

An option with more promise is that the boy may be eligible for participation in a clinical trial, which could offer treatment as part of a research protocol. It would be neither coercive nor unduly influential to offer treatment that the child would not otherwise get through research.<sup>13</sup> And, despite the deep unfairness of the background circumstances, it would not be wrongful exploitation to suggest research participation in these circumstances.<sup>14</sup> Remember, roughly half of patients with cancer who are <15 years of age participate in clinical trials.<sup>15</sup> The physicians should see if such an option is available and refer the patient if he is eligible. The family would likely still face some out-of-pocket expenses if they chose to participate in the research, but these might be more in line with their resources.

At a minimum, the decision not to provide HCT should be clearly explained to the family. They should leave the conversation reassured that all patients in similar situations would be treated similarly and that rationing decisions, however painful, are made consistently. To that end, the children's hospital should have (and follow) a formal policy

that outlines the criteria by which uncompensated care is allocated to both US and international patients. Finally, care should be transitioned back to the medical team in Eastern Europe to ensure that the boy receives appropriate palliative care at the end of his too-short life.

**Jeffrey P. Brosco, MD, and Kenneth W. Goodman, PhD, Comment**

The public hospital at which these 2 authors work is 5.3 miles from Miami International Airport, a gateway to Latin America and the Caribbean. It is not uncommon in our county, where half of the population was born outside of the United States, for hospitals like ours to face cases that involve international patients. As we write this, our ethics committee is consulting on the case of a young boy who came to our pediatric emergency department with the following chief complaint, as voiced by his father: "[M]y son has relapsed leukemia and needs a transplant; his older sister is a perfect match." Unable to do the transplant, physicians in his home country apparently obtained HLA typing and advised the family to go to the United States.

The family perspective is easy to grasp. If the only way to save a child's life is to come to the United States for treatment, many will make the risky and expensive journey, mortgage the house, flout immigration regulations, whatever it takes. We hear from them how hard it can be to separate from family back home and enter a strange land where language, rules, and customs seem alien. Many families come empty handed, asking us to save their child's life.

The clinician's duty seems straightforward: provide appropriate care to the child in front of you. Our training and health care system is focused on the clinician's responsibility to care for the individual regardless of cost. If the standard of care for relapsed leukemia is reinduction and a bone

marrow transplant, then advocate for your patient to get that.

The hospital administration's perspective can be harder for clinicians and families to appreciate. Faced with limited resources and multiple obligations, administrators have a duty to maximize the utility of available resources, especially in a publicly financed hospital. How should they balance the appeal of the 1 child against plans to build an outpatient pharmacy, create a new teaching position, expand quality improvement efforts, or fund the palliative-care team?

One way to untangle the conflicting duties and perspectives of the patient and family, the clinician, and the institution is to apply a modified version of Feudtner's<sup>16</sup> model of staged decision-making. By separating the process into 5 tasks, we can divide the responsibility for discrete decisions among various stakeholders.

In the first step, the clinician and family describe the problem: a child needs standard medical care but cannot afford it. In the second stage (defining the range of possible actions), the family and clinician are not involved in making the decision. Instead, the broader community considers scientific evidence and community standards to set boundaries for appropriate next steps. Institutional ethics committees have a critical role in this stage. A broadly representative group of people can apply moral reasoning to the specific facts of the case (what is the prognosis? the cost? the consequences?). At our institution, we have worked with other local children's hospitals to create a "super-ethics committee" to help identify a community standard in particularly difficult cases. It is at this stage that the conflicting duties of the clinicians and the institution can be debated without jeopardizing the clinician-patient relationship or

relying on an administrator to make an emotionally difficult choice.

The third step occurs within the range specified by step 2. The clinician recommends a course of action on the basis of the facts and some knowledge of the family's values. This would presumably be to provide a bone marrow transplant if the ethics committee concurred. The fourth step returns to the institution and its willingness to offer such treatment: given the needs of the child, the recommendations of the clinician, and the advice of the ethics committee, will the institution offer the treatment? In the final step, the family alone chooses among available options. Most will want to follow through with definitive treatment, although some families may view returning to their home country as preferable to the on-going financial and emotional burdens of treatment in the United States.

This process often reveals obligations of each of the parties. The family adheres to the medical plan and raises funds through charities, extended family, benefactors, and social media (indeed, raising separate ethical issues). The clinician searches for alternatives (eg, other institutions with research protocols and available funds) and works closely with clinicians in the family's home country to maximize treatment of the child there. Hospitals and universities, especially those, such as ours, with large training programs and many international medical graduates, have a responsibility to help build capacity in countries from which many of our patients come. Institutions can also appeal to the larger community for support. We have petitioned foreign governments to support the care of their citizens in our hospital. As a "safety net" hospital, we have also had some success in appealing to local sister institutions and government at all levels for supplementary funding. Institutional ethics committees

carry a special burden to make difficult decisions. It is not enough to implore the institution to provide care in every case; nor should an ethics committee provide cover for an institution that is focused only on financial obligations. In years past, we have said "yes" to a liver transplant for 1 child and "no" to another. The facts in each case matter. We consider prognosis, availability of posttransplant resources, and the longevity of the clinician-patient relationship before the transplant request.

Finally, all parties should engage in the messy political process of trying to define policies that are both humane and financially sustainable. At the local level, for example, our hospital has worked with other providers to arrange routine outpatient dialysis for people with chronic renal failure and no health insurance. This approach is better for the health of immigrants of indigent status and less expensive than urgent dialysis in the emergency department. More generally, clear policies can help clinicians to establish expectations early in the relationship with an international patient.

At the state and national level, sentiment regarding immigration fluctuates in decades-long cycles. At times, we have welcomed foreigners to populate the land and build our nation; at other times in our history, we have restricted their entry and blamed recent arrivals for social ills.<sup>17,18</sup> Health care providers and administrators are sometimes caught trying to care for specific patients amid larger trends that seem beyond our control. As political actors with stories to tell, we can clamor for more support from fellow citizens as we define our nation and plot its future.

#### **John D. Lantos, MD, Comments**

There has always been tension between the ethics of medicine

and the ethics of health care administration. Doctors should not consider the costs of treatment as they advocate for their patients. Administrators must consider those costs. Doctors should be fiercely loyal advocates for the patients in their care. Administrators must consider populations of patients and statistical lives.<sup>19</sup> The conflicts between these 2 sets of ethical commitments inevitably lead to tragic choices.<sup>20</sup>

The guiding ethical principles for tragic choices are that (1) they should be made transparently and (2) they should be as equitable as possible. Equity is difficult to consider when resources are allocated among citizens of rich countries and those of poor countries.<sup>21</sup> As these analyses suggest, hospitals are community resources. They have geographic boundaries that define their moral commitments. That is an uncomfortable truth but an unavoidable one.

Physicians should stick to their guns and advocate for therapies that are best for their patients. In most such situations, they will not prevail. But in some, they will. And losing is better than compromising on an ethical principle that is central to the profession.

*All of the cases in Ethics Rounds are based on real events. Some incorporate elements of a number of different cases in order to better highlight a specific ethical dilemma.*

#### **ABBREVIATIONS**

ALL: acute lymphocytic leukemia  
HCT: hematopoietic cell transplantation

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