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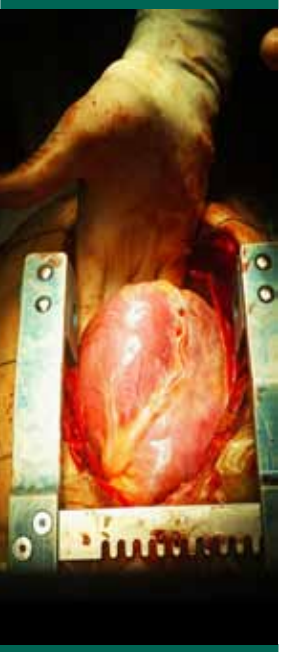

TRANSPLANT

features

in practice

MedStar Washington Hospital Center

mission

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The mission of the John J. Lynch MD Center for Ethics at MedStar Washington Hospital Center is to help clinicians and other hospital professionals meet a standard of excellence in the care of our patients through education, training, consultation, policy development, and research in clinical ethics. Additionally, when appropriate, we address the ethical concerns of our patients and families directly. The MedStar Washington Hospital Center's bioethics program began in 1982. The John J. Lynch MD Center for Ethics, subsequently established, is involved in over 300 clinical ethics consultations a year, as well as the development of internationally recognized bioethics conferences and education programming.

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CENTER FOR ETHICS
AT MEDSTAR
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JOURNAL OF HOSPITAL ETHICS

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contents

Dedication

About 40 years ago, Georgetown University Hospital performed its first kidney transplant. At a mere 17 years of age, Brenda Hudson received a kidney from her sister, a living donor. It took until 2015 for Brenda to experience kidney failure again, after which she was fortunate enough to receive a second kidney from yet another living donor. This time, it was her husband of 7 years. What is remarkable about Brenda's case is the number of years she was able to maintain healthy kidney function after her first procedure (the anticipatable average is around 17 to 18 years). Likely her age and familial donor had some effect on the unprecedented number of successful years.[1] Most of those in need of an organ, however, are not so fortunate. The vast majority of organ donations occur anonymously and via waiting list. The decision to donate an organ to a family member or friend, or choosing to assume the status of organ donor for postmortem transplantation, nevertheless are both actions of critical support to a system that devotes its efforts to prolonging the healthy lives of critically ill persons by relying on the generosity of others.

Some might argue that the rights and privileges that avail from a transplant system can only be sustained if we recognize and act on a corresponding duty to donate. Simply, the system itself would collapse without it. In 2016, out of 41,335 donations in the U.S., 35,360 were postmortem, while only 5,5976 came from living donors. In fact, only about half (54%) of the population of the United States, throughout the same period, were registered as postmortem organ donors.[2] And 115,332 is the present number of combined persons (that is, all from each organ-specific list) waiting for a suitable organ, with a new candidate added to the list, on average, every 10 minutes.[3] One might gaze at these numbers and consider (short of a technological optimism about what regenerative medical science will ultimately yield in terms of synthetic organ reproduction if unrestricted in its work) that the system, as it stands, is collapsing already. Perhaps this was never sustainable, as we witness in addition to an increasing and arguably unnecessary loss of life, each year, a growth rate of the number of persons on the national list that is significantly faster than either the number of registered donors or transplant procedures.

In 2010, another person in need of a kidney was offered that of a nonfamilial, postmortem donor, and almost 8 years later is another successful transplant case. I would like to dedicate our Transplant issue to that person, my mother, Maria Carrozzo. She expresses her gratitude in various ways, daily, free of the often cumbersome and debilitating process of dialysis, now spent happily as she always has with those she loves and cherishes, including her husband of 50 years. Adhering to her self-care regimen also honors the

opportunity given to her, something she considers a minimal responsibility, and one easily motivated by the intuitive desire to maintain her own good health as well as in return for what she has received. If she has anything to communicate to the remaining 46% of persons who are not registered as donors, it would be to perhaps examine how broadly one can expand one's circle of empathy and lay down the kind of limited reasoning that encourages nonregistration, by stifling any sense of corresponding duty to a system that someday may very well save your life. That perhaps imagining one's mother, daughter, or son as needing to rely on an anonymous postmortem donor in the absence of an able family member might influence a change in one's standpoint on donation. Indeed, we as family are also grateful for the woman who decided to register as a donor so many undisclosed years ago, and although she experienced a relatively young death, gave my mother, and who knows how many others, their life back.

Christian Carrozzo, Senior Editor

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A Bridge to Transplant

Dear Reader,

Welcome to volume 5, issue number 1 of the *Journal of Hospital Ethics* (*JOHE*). This issue explores one of the most technically complex and ethically challenging areas in hospital medicine today. Transplantation medicine is a field as scientifically and ethically difficult, fascinating, and rewarding as they come.

But as with so many medical marvels, the planning for ethically complex details lags behind the science. That is not to say there hasn't been much ethical consideration given to many of the relevant issues that are woven into the fabric of transplantation. Some of the big ethical questions that are posed by transplantation include those that are centuries old in medicine and have been debated since the early days of transplantation: issues of justice and fairness continue to arise. The questions of insurance coverage, especially for outpatient support services, plague every United States (US) transplant center. Hospital ethicists and ethics committee members attached to transplant units and/or transplant centers have their hands full.

For about the last 5 years I have been attached to the advance heart failure (AHF) program at our hospital. Although we used to do kidneys, that work has moved to our sister hospital and colleagues at Georgetown University, where they also perform various other organ and tissue transplants. Now, at least as far as the solid organs go, we only do hearts. Thus, of the little I have learned about transplant medicine, virtually all of it has been contextualized by cardiologic practice. In this issue, we have sought to include a spread of ethical complexities that influence decisions for many organ and tissue transplants. However, because it is what I live, and because none of our other authors has touched on it, I want to turn to an ethical complexity that is specific to heart transplantation: that is, the lack of outpatient services for persons having problems related to their ventricular assist devices (VADs).

VADs, or what are also known as mechanical circulatory support devices, are implantable mechanical pumps that assist blood from the lower chambers of the heart to circulate throughout one's body. When one has a VAD, one no longer has the standard beat of a normal heart. While listening to the chest of a patient with a VAD, one hears a pulsing whoosh. Hearing that sound once is enough to realize that a VAD is a quite specialized device.

VADs get implanted for various reasons, but, for our purposes here, I am restricting my comments to those VADs (most commonly, left ventricular assist devices or LVADs) implanted as a bridge to transplant (BTT). These are the VADs that keep people with failing hearts going while they wait for an available organ.

Time on a transplant list can be nail-biting for a patient and his or her family and friends. We have a window into that world from the patient's perspective in the poetry of award winning American poet Dean Young. Young was born in 1955, and, since 2008, has been the William Livingston Chair of Poetry at the Michener Center for Writers at the University of Texas at Austin. Young was a heart recipient in 2011 after several years of illness. A prolific poet, in 2015 Young published his first post-transplant poetry collection, titled *Shock by Shock*.[1] His poem, "How I Got Through My Last Day on the Transplant List" is revealing of just how stressful such a day can be. Nonetheless, getting a heart makes almost whatever it takes to survive long enough to get that heart worth the wait. Since *Shock by Shock* was published, Young has had the opportunity to publish several more collections.

Yet while one waits with a VAD, sometimes circumstances become heartbreaking. One of the more common, anticipatable complications of a VAD is stroke. If a stroke robs the patient of the cognitive capacity required to self-manage the VAD, patient care can get complicated, quickly.

Because hearts are such a scarce resource, and heart failure is increasingly hitting hospital shores everywhere in the technologically advanced world, more and more patients are receiving BTT VADs. Ethically, at least in the US, one of the biggest problems is that, for the patient whose stroke has left her or him too impaired to self-manage a VAD, even if the expectation is that the patient could recover his or her cognitive function and VAD self-care might be returned, it is the family who is going to have to take care of that patient. Community care for VAD patients, for example in nursing homes and other community high-tech hospital-like settings, is not prevalent.

Once it has been decided, medically, that a patient who is eligible for the heart transplant list is unlikely to first receive a heart transplant and will most likely need a BTT VAD, and possible financial issues have been sufficiently addressed for the patient to be cleared for the procedure, the last hurdle for the patient is social support. When it comes to heart transplantation, social support serves as a criterion for eligibility.

For many transplant patients and living donors, part of the evaluation process is an assessment of psychosocial factors. But there is little if any specification included in these assessments of what would count as insufficient social support. Given this, any derivative criteria for what should be present in the way of appropriate support for VADs is also lacking.

In the absence of knowing what level and/or kinds of social support might be needed in the case of VAD complications, such as a cognitively debilitating stroke, even when family and friends rally around a patient who needs a heart transplant, it is often the case that those family members and friends, who offer their time to take care of the patient, might not yet fully appreciate the possibilities or simply underestimated what might be required of them. When a patient has a stroke, as horrible as it is, if the stroke leaves the patient with no expectation of regaining meaningful cognitive function and, for example, he or she is nonresponsive, in most cases, addressing that patient's situation is ethically straightforward. Albeit terribly sad, it is ethically uncomplicated to help the family shift the patient's plan of care from awaiting heart transplant to hospice. But, when a patient has had a stroke that is expected to be irreversible with no reasonable expectation of any meaningful recovery, although left cognitively debilitated and unable to self-manage the VAD, this patient might be well enough to watch TV, eat, laugh, walk the halls with assistance, and talk to family, although the patient might not recognize them. This patient's case illuminates ethically dire complexities. Without the needed community settings, it is most likely the case that the patient is going to be moved home with his or her family.

Try as the family might, however, they are likely to be strained beyond their ability to cope. Without community settings where such a patient can be moved, families and friends are just flat-

If a stroke robs the patient of the cognitive capacity required to self-manage the VAD, patient care can get complicated, quickly.

tened under the weight of patient care. Often such a patient bounces back to the hospital transplant center, where she or he is safe, but it is not the kind of facility that is appropriately equipped to take custodial care of patients who are no longer eligible for the heart they were previously awaiting.

The burdens such a situation can result in are far greater than financial. Transplant nurses and physicians are trained to take care of acutely, critically ill patients, not the patient just described who might live years with an LVAD, if nevertheless cognitively disabled. Care of the patient here discussed only frustrates such clinicians because it is not the kind of care for which they are trained nor are interested in providing. Of course, the financial strains are significant; just thinking about the costs of an excessive length of stay for a patient in an acute care hospital these days makes everyone's hair stand on end. But the emotional and moral drain on clinicians, for me, is an even greater concern. Burnout has serious consequences for a fast-paced, critical-care transplant team.

It is a tall order to ask transplant programs to take on the extra effort required to cultivate community resources for impaired VAD patients. And here I'll just take up a little space to congratulate our AHF program for reaching out to our community long-term care and hospice providers to build links with them for our patients who might need them. Our AHF program has had some success. We now have hospices that will go into patient's homes if turning off a VAD is what a patient needs, and there are select hospices in other parts of the US that will care for VAD patients, as well. Our VAD team also has built bridges to a small number of nursing homes that have indicated a willingness to take a VAD patient as long as our team commits to training the nursing home staff.

But more work must be done. According to US Department of Health and Human Services (DHHS)'s Health Resources and Services Administration (HRSA), the US passed the 30,000 mark for transplants in 2015, with United Network for Organ Sharing (UNOS) data indicating that that number is up to more than 34,000 transplants annually. According to additional data from UNOS, there have been more than 68,000 heart transplants since the beginning of their data collection in 1988, and more than 114,000 patients need an organ transplant, with more than 78,000 of these actively on waiting lists.

When a heart transplant is performed on a patient who is less than 55 years old and everything goes smoothly, it is possible that the heart may last another 10 years. That's a lot of time, and VADs expand these possibilities.

And so, although this is a lot to ask, it seems to me that some of the time and resources of a transplant center ought to be put aside for something like "community outreach." Funding considerations aside, working with community facilities to identify and train those who will take VAD patients, when needed, is an imperative if VADs are going to continue to be implanted into an increasing number of patients. Of all the seemingly intractable ethical complexities transplant medicine produces, this one, although onerous, might just be one we can solve.

Turning to this issue of *JOHE,* we present three very different and excellent feature articles. The first is written by my dear colleague of decades, Sigrid Fry-Revere. Since we met during my National Institute of Health (NIH) days, I have known Dr. Fry-Revere to have labored long in the field of transplantation. She raises an important possibility for how to make living donation more fair and reasonable financially for the living donors. It doesn't seem fair to ask donors to take on the costs of complications and lost work days. This semester, I am one of a small group of facilitators at the Georgetown Medical School ethics program, and while discussing the unseemliness of selling organs, I asked them what they thought about expense reimbursement for living donors. They unanimously thought that the idea was fair and good.

As Laura Guidry-Grimes discusses so cogently, everyone recognizes donated organs and tissues as

It is a tall order to ask transplant programs to take on the extra effort required to cultivate community resources for impaired VAD patients.

gifts. It seems that the donation is gift enough; one ought not to make the giver keep paying if things go wrong. Dr. Guidry-Grimes's work reminds us not to place undue moral weight on recipients when organs go bad, and it seems to me this can be linked intellectually to Michael Pottash's piece in this issue. Dr. Pottash illuminates the collision course of two requirements of the Centers for Medicare & Medicaid Services (CMS): one requires the reporting of deaths in transplant programs and the other requires palliative care services to be involved in at least certain kinds of transplant cases.

Like ethics, it seems that palliative care (although to a lesser extent) is invariably called into a complicated case, and often too late. In the context of Dr. Pottash's article, the reporting requirements do seem to act as a barrier to calling palliative care in early. Fear on the part of transplant team members that palliative care (like ethics, but that's a different conversation I'll force myself to save for another issue) is more inclined to suggest hospice sooner than they are, acts as a disincentive for patients to receive the benefits of having palliative care assist in the control of noxious symptoms. If palliative care does suggest that hospice be an option that is presented to a patient and his or her surrogate(s), if that is what would be best for the patient—even if that would adversely affect a transplant program's morbidity statistics—then we suggest that the morbidity statistics take a back seat. But that's easier for me to say than it is for a program director, for example, who must carry considerations of protecting a program's viability. This collision course, where patient care is caught in the middle, seems to be a prime example of the unintended consequences of good intentions. On the one hand, CMS wants to assure high standards for medical excellence, *ergo* its morbidity reporting requirements. On the other, this problem shows how important palliative care services can be to patients, families, and clinicians. This problem might be at least mitigated with some creative thinking about how morbidity statistics are collected and reported.

As to the cases included in our "In Practice" section, the first case, divided into two parts, shows how—even in the face of the loss of a functioning transplanted organ—concern for the patient's overall well-being and the physician's intent to avoid doing things that will do the patient more harm than good (even over the objections of the family) are marks of excellent medicine. Further, this is a perfect example of when physicians' discretion should be retained, even when the preferences of families are given ever-increasing weight.

The third case, to which I contributed, brought the issue of complexity of care into new focus for me. As my colleagues of long-standing know, I have been interested in complexity in clinical care ever since I arrived at Medstar Washington Hospital Center from the NIH. The messiness of patient care in today's world of high-tech medicine calls for new ways of thinking about complexities, medical and ethical. This includes modern diagnostics.

As I was working on the case, the 5 principles of high-reliability organizations (HROs) came to mind. My hospital has long been an HRO hospital, working to avoid accidents, despite being a high-risk organization. Of the 5 principles, the second, reluctance to simplify, is relevant to the case of the patient whose diagnosis was missed; reluctance to simplify is comparable to the notion of "embracing zebras," which I discuss. In both cases, teaching is evolving toward the provision of explicit strategies to manage complexity. Although deep-rooted educational approaches are difficult to replace, it is gratifying to know that efforts are afoot in medical education, from different directions, to evolve in this way.

We hope you like this issue. And we would love to hear your thoughts.

Sincerely,

Evan
Evan G. DeRenzo, PhD, Editor-in-Chief

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Solving the Organ Shortage by Giving Living Organ Donors What They Deserve

Sigrid Fry-Revere, JD, PhD

INTRODUCTION

This is an opinion piece by a medical ethicist who has dealt with living organ donor issues for almost 30 years both professionally and personally. I also tried to become a living organ donor eight years ago and was excluded for financial reasons. My friend died. Last year, when I tried again, I was excluded for medical reasons. For the past four years, I've worked as a full-time volunteer helping living organ donors. At first as the president and chief executive officer of the American Living Organ Donor Fund (ALODF), but now as the vice-president for living organ donor relations at the break-away organization Kid-U-Not Living Organ Donor Fund. I personally have worked with over 300 living organ donors. These organizations do not just provide funds to cover expenses such as lost wages; they help in whatever way living organ donors say they need help, as long as that help is related to living organ donation and within their charity mission. The work I've done and continue to do includes but is not limited to helping living organ donors by providing information, medical and financial; navigating the grant process at government agencies and other charities; communicating donors' needs to their recipients, employers, insurance companies, transplant centers, and policy makers; finding professional expertise outside my own, such as medical, legal, psychological, or financial counseling; and providing a forum for peer support. Resources are available to all living organ donors and those considering donation, regardless of the organ they are donating or their financial status. Most donors seek help before their donation surgery, but we help donors just as readily if they run into medical or financial problems post-donation. Many of the living organ donors who seek assistance need help at a specific time of crisis, but others have maintained a supportive relationship with the organization that helped them for years. Neither organization encourages or discourages living organ donation.

At a time in history when political alignments have become entrenched, it is more important than ever to look past our personal ideologies and listen to what those who are directly affected have to say. Many of the most vocal advocates for various living organ donation policies refuse to change their positions even in the face of new evidence. One scholar to whom I was explaining why I changed my mind about incentives told me she wasn't going to listen to wishy-washy grey arguments because she had a brand to protect. In other words, she had a reputation for advocating a certain position and wasn't going to risk her income or notoriety by changing it. On the other hand, a transplant surgeon who has been against incentives for decades told me he didn't believe I had changed my mind, that he was sure I was advocating for a policy I intended to be

a step towards paying people to donate. The truth is, I've changed my mind after listening to living organ donors. If we are going to find a solution to the organ shortage, we need to listen to those who have donated or who are in the process of donating rather than to the general public, recipients, or others who have no firsthand experience with trying to become a living organ donor.

In the 1980s most policy makers, ethicists, and those in the transplant community thought that the organ shortage could be solved with organs from the recently deceased. A valid ethical argument was, and still is, that we should not put living persons at risk if there are deceased donor organs available. This argument is still valid and justifies doing whatever we can to increase deceased organ donation, but even if every American agreed to be a deceased organ donor, the supply of organs from the recently deceased would never suffice.[1] When Congress was debating passage of the National Organ Transplant Act in 1983 there were approximately 10,000 people waiting for organs.[2] In 2016 there were 27,981 transplants from 13,431 deceased donors. (These numbers are not all transplants from any source and not all organs retrieved, because this number excludes organs retrieved but never transplanted. Thus, this number is the actual number of organs used. Note, this number does not account for the number of transplanted organs that fail either immediately or within a short time after transplant.)[3] If the number of people waiting for organs hadn't increased, the current number of deceased organ donations would have been almost three times more than needed. But, unfortunately, the need has grown disproportionately to the supply, and, as of this writing, there are almost 117,000 people waiting for organs.[4] Possible long-term solutions include artificial or bio-engineered organs and xenotransplantation, but the only viable short-term solution is finding a way to increase living organ donation. The need for organs is clearly dire, but we can't let our desire to help those on the waiting list cloud our judgment about what is fair and ethical for living organ donors.

This opinion piece provides some informed insights based on my personal observations working with living organ donors for the past three years. This is neither a scientific study, nor an organized survey, just my personal observations. But, even given these limitations, the ideas presented here are worth consideration.

It is my firm belief that the only ethical way to solve the organ shortage is to change how we conceptualize living organ donation. Living organ donors are people and patients. No one likes being treated as a source for organs. Yes, the United States economy treats people as resources all the time, for example, "human resources" and the labor market. But the medical community goes to great lengths to try to prevent patients from feeling as if medicine is merely about hospitals and doctors making money. How successful the medical community is at achieving respect for its patients is not the issue. The point is that we need to make the same effort for living organ donors that we do for other patients. They are no less autonomous moral agents than organ recipients. As we consider living organ donor policies, we need to ask ourselves, "Do we treat other patients like that? Is this how we treat transplant recipients?" We need to change how we think, talk, and provide services to living organ donors so that what we do reflects what living organ donors want and need. Only then is there a chance that we can find an ethical way to increase living organ donation.

Even if every American agreed to be a deceased organ donor, the supply of organs from the recently deceased would never suffice.

Here are three practical considerations for how our transplant system can improve based on my interaction with living organ donors and those considering donation:

1. We need to provide living organ donors with more comprehensive and more accurate medical and financial information to help them decide whether to donate, to prepare them for donation, and to help them deal with post-donation medical and financial complications should they arise.

2. We should abandon any idea of encouraging donation by offering donors money, nonfinancial incentives, or other nondonation-related benefits. Incentives geared at tempting people to donate are degrading, will create an unjust boon-or-bust situation, and do not provide donors with the type of benefits they need to feel secure about donating.

3. We need to take a closer look at the two countries in the world that have the highest rate of organ donation per million population—Iran and the Netherlands[5]—and ask, "Which of these two systems is more successful and why?" and "Which would serve as a better model for US policies, given our cultural, governmental, and economic differences?"

INFORMATION

It is my observation that living organ donors ask for three different types of information. The first is the information needed to make a wise decision regarding whether to donate. The second is the information needed to prepare for donation and its aftermath. And the third is the information needed to deal with complications, should they arise. But, I've noticed that not all donors want to avail themselves of such information equally.

There seems to be an inverse correlation between the amount of information a donor wants before the donation and the closeness of the donor's relationship to the recipient. Of course, there are exceptions, but as a rule, the closer the relationship, the less a donor wants to know before the donation. The attitude is something like, "I'll do anything to save my loved one, just tell me what to do." As an illustrative example, consider the understandable difference in attitude towards donation between donor parents and donors who barely know their recipients. According to the observations I've made, the parent is not going to listen closely to the risks of donation, nor is the parent going to care much about preparing for potential complications post-donation. Parents are usually focused on saving their child. On the other hand, donors considering donation to an acquaintance generally seek more information about the risks of donation before they make a decision to donate.

A confounding factor is when donors have conflicting obligations. Regardless of their relationship to the organ recipient, donors with dependents tend to be more risk-averse and ask more questions when the recipient isn't one of those dependents. For example, a potential donor faces a dilemma when a donation to a stranger, acquaintance, friend, or relative other than the donor's own spouse or child means the donor's immediate family will suffer, for example, have trouble paying monthly bills.

Almost uniformly, however, when it comes to the third category of information—that is, information for how to deal with complications when they arise post-donation—donors want to access in-depth information as soon as possible. Frustration and anxiety mount when donors can't reach anyone at the transplant center to answer their questions and internet searches prove fruitless or confusing.

From a practical standpoint, the charities I've worked with cannot provide medical advice, but while I was still at the ALODF, I thought an easily understood database that allowed donors to gather information at their convenience for each of the three types of decisions described above would empower donors and facilitate every step of the donation process. That information would need to be readily accessible, accurate, easily understood, and include resources for how to deal with complications.

The point is that we need to make the same effort for living organ donors that we do for other patients.

I set out to create such a database, but with little success. I started by asking living kidney and liver donors to share the complications they had experienced. Then, volunteers looked for medical articles to confirm whether those complications were related to the organ donation. And, if so, in what percentage of cases the complications arose and how they were treated. I was sorely disappointed by how little information there was and how hard it was to decipher. We found little medical research to support conclusions about any but the most common surgical complications.[6] The

ALODF list of potential complications was still incomplete and unreliable when I left in April 2018. Certainly, part of the issue is that the ALODF didn't have the resources to complete such an extensive project, but even if the resources were available, for some of the complications, particularly long-term complications, there are little or no data, let alone reliable data. The medical community needs to work both to make more information easily available and to be more forthright about what is not known with respect to both short-term and long-term complications.

but wonder how many kidney donors are taking unnecessary risks with their remaining kidney just because they were misled, or because a misconception wasn't corrected. And what about the emergency room doctors: why didn't they know that they shouldn't give contrast dye to a living kidney donor? How many other similar mistakes are being made by donors and their doctors? For example, how many female kidney donors of childbearing age know they have a significant increased risk of pre-eclampsia and gestational hypertension?[7] For that matter, how many obstetricians know this?

I was shocked by the number of donors in the online "Living Donor Support Group" who didn't know they needed to take precautions to protect their remaining kidney.

I also noticed that donors often have misconceptions regarding the known long-term risks of donation. In the online "Living Donor Support Group," I once posted, with the subject line "How to Take Care of Your Remaining Kidney," a warning about kidney-toxic medications and suggested that donors take precautions to monitor their kidney function whenever their body gets stressed, for example, during pregnancy or illness. The reason I made the post was that a donor had called me the night before and told me a story about feeling pain and going to the local emergency room, where they did a scan using contrast dye, damaging his remaining kidney. I was shocked by the number of donors in the online "Living Donor Support Group" who didn't know they needed to take precautions to protect their remaining kidney. I was even more shocked that some of the donors were so upset by the suggestion that they needed to take special precautions, that they called me a "liar," stressing that their doctors had told them they had nothing to worry about post-donation, that they had totally normal kidney function, and that they didn't need to take any special precautions. The debate raged on for days and resulted in several members leaving the group saying "such lies" will scare potential donors. I told the group that the best way to get an answer for their specific situations would be to talk to their personal nephrologist. Again, I was surprised; almost all of them said they did not have a nephrologist. I couldn't help

"What obligation does the medical community or society as a whole have to provide the information discussed above?" For me personally the answer is simple: "Respect for autonomy suggests we should provide as much information in as comprehensible fashion as possible." We can't force people to look at the information we provide or guarantee that they understand it, but we can make it available. I can't help but believe that one reason the type of information discussed here is not made readily available is the fear that it might discourage donation. But, living organ donors, like all patients, have a right to full disclosure of relevant risks and reasonably swift access to helpful information when they suffer even mild complications. I also feel we have a moral obligation to help donors protect their health, and downplaying the need for health precautions post-donation is unethical.

Another important improvement would be for transplant centers to make it easier for donors to find someone at the transplant center to answer questions post-donation. Many donors have complained to me that their only contact at the transplant center is the living organ donor coordinator or a social worker who didn't get back to the donor for days when called with a question. Hence, the many stories of fiascoes when donors go to their local emergency room, some medical and some financial. I once asked a transplant social worker who did a presentation on depression in donors

why her team doesn't call and check on donors two or three days post-donation to see how they are doing. She said, "We don't have the time." I thought, "Wow—my dentist's office called me two days after I had a wisdom tooth pulled to see how I was doing." If dentists' offices can make the time, then so can transplant centers.

The more people from the transplant center reach out to donors post-donation, the more questions about possible complications will be answered, and the less likely it will be that donors feel abandoned by the system. When I asked donors from the support group how many had received calls post-donation, I was shocked at how few of them got a call from the surgical team, let alone the living-organ donor coordinator or a social worker. Some donors told me they had called and no one had returned their call. Increasing such post-operative contact would be a valuable practical step towards getting donors' post-donation questions answered and making them feel more positive about their donation experience.

Note that public surveys indicating that people would be willing to donate a kidney for a certain amount of money or other incentives are practically worthless when the general public has no clear understanding of the risks of donation. When I bring up living organ donation with people who don't have connections to the transplant community, they usually think that medical risks are minimal with no long-term effects, that there are no financial costs associated with donation, and that, if they donated, they would be back at work in a week or so. Where do these misconceptions come from? Probably multiple sources—the media, the transplant community, and even living organ donors themselves—all tending to emphasize the positive, for fear of discouraging potential donors. In terms of incentives to donate, this lack of accurate information makes a survey of the general public all but worthless in terms of cost/benefit analyses.

To some extent, the argument over incentives involves nonproductive semantic hair splitting.

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Whether the issue is a pre- or post-donation medical or financial question, more resources need to be available to help answer donors' questions. Readily available information both online as well as in the form of people the donor can talk to are necessary to help assure informed consent and to help assure that donors get proper care post-donation, both immediately after their donation and long term. The provision of such resources would go a long way towards making donors more comfortable with their decision to donate.

GOOD AND BAD INCENTIVES

I haven't asked every donor I've met if they think paying people to donate is a good idea, but many donors I've interacted with tell me all they need and want is help with their expenses and lost wages so they don't have trouble paying their monthly bills. Going beyond covering actual expenses and losses in the eyes of many donors is not only unnecessary, but also potentially insulting.

I've been told by an economist that removing disincentives is a form of incentive. As true as that may be technically, from a practical standpoint, living organ donors seem to think there are good incentives and bad incentives and that there is a clear conceptual line for distinguishing one from the other. Those incentives that help make living organ donation cost-neutral are clearly more acceptable to living organ donors than those that provide payment in exchange for donating an organ.

Nor is "repugnance" at the thought of selling an organ much of an issue. I have heard a few donors or potential donors mention that the notion of selling body parts is unseemly, but that notion is less important than the fact that living organ donors see being motivated by money as inferior to the kind of motivation that should be in effect when deciding to participate in organ donation. Some donors have expressed that payment, or even nonmonetary incentives intended to motivate people

to donate, create the social perception that donors are motivated by greed, poverty, or mixed motives that reduce the perceived value of the donor's sacrifice. This perception affects both people who have donated and those who might consider donation. Donors tell me that they fear people will not donate if they are perceived as doing so to enrich themselves. Donors want to be seen as loving (a loving mother, a caring sibling), altruistic (someone who is selfless, good, or kind), or as having integrity (a responsible spouse, a loyal friend). In the face of such values as love, altruism, and integrity, the offer of inducements is debasing. In short, there are good incentives and bad ones. Love, altruism, and integrity are good inducements. Money, gifts, or other nondonation-related benefits are bad inducements. And introducing the latter to try to increase living organ donation may reduce the number of people who think the risks are worth the sacrifice, particularly in a country like the US, where there are fewer people who, once they fully understand the risks, will be tempted by financial incentives than in other countries. Economically and socially, the US is more like the Netherlands than Iran. (See the section "Iran, the Netherlands, and Beyond," below.)

This raises some additional questions, for example, if incentives other than love, altruism, and integrity are bad, then how can it be good to help living organ donors financially at all, even if only with their expenses and lost wages? Some donors I've met say that any payment, even in the interest of making donation cost-neutral, devalues their sacrifice. They may be right, but there is a strong countervailing interest that resonates with me and many donors I've spoken to: It is unjust to have a society where living organ donations that are motivated by love, altruism, and integrity are limited to those who are financially well off enough to cover their donation-related expenses and losses. In the US, fewer than 10% of the adult population has paid leave and/or enough money in the bank to cover six weeks of lost wages.[8] Any social program that helps living organ donors with expenses and losses, which they would not have if it weren't for the donation process, levels the playing field without resorting to incentives that might be seen as creating untoward motives. Also, any program that strives to make living organ donation cost-neutral also helps lessen the dilemma faced by donors forced to choose between conflicting obligations, such as the donor who needs to choose between donating an organ and being a reliable breadwinner.

Another unavoidable question is whether the living organ donors I've spoken to are wrong about good and bad incentives, and that all incentives are good. In principle, this is a valid objection: we don't know whether introducing additional incentives beyond love, altruism, and integrity will increase or decrease the number of living organ donors. Maybe those already motivated by love, altruism, and integrity will continue to donate, and those for whom other types of incentives work will increase the number of overall donations. The problem is that the types of incentives currently being considered such as payments—see the OPTN/UNOS white paper on the subject[9]—may result in a boon-or-bust scenario (as is the case in Iran, see below). The other problem with that paper is that it concludes that we should study what incentives the public would find acceptable. As mentioned above, the results of such studies are likely to be skewed because the public doesn't have a clear understanding of the risks and benefits of donation. I'm not saying it would be impossible to create a study that first educates participants on the risks and then asks them what financial incentive might motivate them to donate, but I'm skeptical.

In a boon-or-bust scenario, if such incentives are sufficient to encourage donation, donors with low expenses who are financially secure and have

It is unjust to have a society where living organ donations that are motivated by love, altruism, and integrity are limited to those who are financially well off enough to cover their donation-related expenses and losses.

health and disability benefits would get a windfall. But other types of donors may suffer losses even if a significant payment is offered, namely donors with one or more of the following: unpaid leave, high expenses for travel or child care, no health or disability insurance, complications that require a long leave of absence from work or that result in job loss, or possibly other medical or financial complications I haven't yet seen. I had one donor tell me he had only minimal expenses when he donated. He was a young professional who got three months of paid leave and lived within a metro ride of the transplant center, and whose girlfriend took paid vacation time to care for him after the donation. Such a person would get a windfall in any incentives program that provides more than a token benefit. But what about donors who have significant expenses? How do you create an incentive that is enough to cover potential needs without being a windfall and still tempts people to donate? I once helped a donor who ended up $400,000 in debt because of kidney donation complications. The transplant center could not bill the recipient's insurance because she had gone back to work and dropped her Medicare coverage. Since the donor had no insurance of her own, there was no coverage at all for her medical bills. Other donors I've worked with lost their jobs. And yet others were permanently disabled and needed to go on dialysis themselves. How far does whatever incentive is being considered, whether $10,000 or $40,000, go in these cases? Whatever program is created to help living organ donors, it needs to be tied to real needs, not incentives that may be a windfall to some and not be enough to cover donation-related expenses for others.

Whatever program is created to help living organ donors, it needs to be tied to real needs, not incentives that may be a windfall to some and not be enough to cover donation-related expenses for others.

Creating a boon-or-bust system is inherently unfair. Incentives are likely to further advantage those who already have economic advantages and put those who don't at risk of total financial disaster. The only types of incentives that wouldn't have a boon-or-bust effect are the cost-neutral, "good incentives" mentioned above. These would be benefits that are directly related to each donor's specific needs. For example, coverage of actual travel, lodging, and related expenses as they occur (as the National Living Donor Assistance Center—NLDAC—program does for all donors), short and long-term disability benefits, healthcare coverage, job security, and any other directly donation-related expense (for example, child care, pet care, house sitting costs). The key would be to make sure all donors have equal access to these benefits if they need them. A system that aims to reduce the financial and medical risks associated with donation by providing all donors with access to the same opportunities and benefits, should they be needed, is far more just than a system that tries to entice people to donate by offering them incentives that are either superfluous to their actual donation-related needs or inadequate, should they face medical or financial complications. See my TEDx talk for more specific ideas on how the US could achieve these policy goals.[10]

IRAN, THE NETHERLANDS, AND BEYOND

In 2008 I spent two months interviewing living organ donors in Iran because, at the time, Iran had, by far, the highest rate of living organ donation in the world. One important factor in creating such a relatively high living organ donor rate was that Iran was the only country where financial compensation beyond a donor's expenses or lost wages was legal, regulated, and subsidized by the national government for more than a decade. In other words, living organ donation in Iran was and is highly incentivized. As I report in my book about my field research in Iran,[11] the incentives offered to living kidney donors in Iran ranged from payments and gifts to healthcare and job services. Benefits, in cash and in kind, could total as much as $40,000, in terms of comparative Iran/US buying power.

I reported mixed results as far as how donors felt about their donations. One interesting observation was the number of donors who didn't want anyone to know they donated. When asked why they didn't want others to know about their donation, the answer usually had something to do with not wanting others to know they needed money. Even in a country where paying living organ donors is legal, donors felt a stigma associated with donating for money. In the eyes of donors, and perhaps most Iranians, donating an organ for money is something people only do as a last resort. Thus, donating an organ was seen as evidence of financial desperation and a failure to care for one's family in a conventional manner. No matter how hard the Iranian government tries to portray donors as heroes, the mere fact that money exchanges hands creates a social stigma that has nothing to do with repugnance or the ethics of "selling an organ," but rather with the impression society has that those who sell their organs are in some way social failures. Whether donors actually are financially desperate is irrelevant. What mattered was that people assumed they were either desperate or greedy—some of the donors I came across in Iran were using the money to improve their businesses or homes, and thus were not financially desperate. One donor I interviewed in Kermanshah felt guilt that she was using the money to build an addition on her house when others had no homes at all. That is, she feared people would see her as greedy. Like American living organ donors, many Iranian donors wanted to be seen as motivated by love, altruism, and integrity, but they couldn't escape the impression that they were motivated by money. Clearly, while these negative impressions exist, they didn't dissuade many donors in Iran from donating. As a matter of fact, many of the donors I interviewed in Iran were donating because of extreme indebtedness, and some were even being threatened with debtors' prison, something that doesn't exist in the US.

Also in Iran, since the compensation allowed living organ donors has a fixed range set by government guidelines and convention, Iranian donors suffer from the boon-or-bust scenario described above. Some donors, particularly those who have no complications and can return to their jobs shortly after donating, come out ahead financially. Others, particularly the unemployed or those with extreme debt, don't improve their situation much or for long.

Another interesting fact is that, in Iran, over 90% of all donations are from strangers, not relatives.[12] When I asked recipients why they didn't have a relative or friend donate, I got several interesting responses, but the one that is most relevant for this discussion was similar to the argument I gave at the beginning of this article for preferring organs from the recently deceased to those from living organ donors. That is, it was ethically preferable to not put a living person at risk if an alternative is available, like organs from the recently deceased. In Iran, recipient after recipient said they felt it was ethically more acceptable to put a stranger at risk than a relative. In one case, a woman with seven children said she had to sell part of the family farm to pay her donor, but that she would much rather do that than put one of her children at risk. This attitude begs the question, "Do we want to create policies that treat donors as second-class citizens because we would rather risk their lives than ask a loved one or friend to risk their life for us?"

So, some important questions must be asked. Does the US have a readily available population who would be willing, if accurately informed, to take the risk of donating an organ for money? If yes, how much money would it take—if they truly understood the risks? And, even if we could find the price point for tempting Americans to donate, would it be right to do so? The notion that it is wrong to tempt the poor to donate is why some people suggest the US should adopt nominal or

In the Netherlands, living organ donors have paid leave, job security, lifetime health coverage, and even a special government fund to help with donation-related incidentals, like child care.

minimal incentives. But, as any economist will tell you, the lower the incentive, the fewer people will be tempted by that incentive to donate. I left Iran wondering if there was a way around these problems. The most important of which I thought was whether it was possible to pay donors and not have them end up feeling like second-class citizens. Then, last year I learned that the Netherlands had just surpassed Iran in its number of living organ donors per million without paying donors. Maybe, I thought, we don't need to resolve the many issues financial incentives create. Maybe there is another way.

In 2016, the Netherlands exceeded Iran in the number of living organ donors per million by doing exactly the types of things US living organ donors have been telling me they need. In the Netherlands, no money exchanges hands, and there are no nondonation-related incentives, only the cost-neutral type of incentives mentioned in the above discussion of good and bad incentives. In the Netherlands, living organ donors have paid leave, job security, lifetime health coverage, and even a special government fund to help with donation-related incidentals, like child care. In the Netherlands, there is no boon-or-bust scenario because their living organ donor policies cover expenses and create medical and financial security for those who already have nonfinancial motives to donate. Interestingly, in the Netherlands, in 2016, over 70% of donors were relatives by blood or marriage,[13] making me think that the motives American living organ donors told me they favor, namely love, altruism, and integrity, are the motives that prevail in the Netherlands (personal communication with Elise van Hees, Public Informations Officer for the Netherlands Society for Transplantation Statistics, October 13, 2017). It certainly isn't incentives, like those in Iran or those suggested by some in the US, that have allowed the Netherlands to outstrip Iran in its per million rate of living organ donation, because the Netherlands has achieved its high donor rate without such incentives.

Under these circumstances, it is obvious that we need a better understanding of American living organ donors' needs and wants, and how to satisfy them. It seems to me that the Netherlands provides evidence that it is possible to create a successful living organ donor system that treats donors with respect and dignity and that doesn't insult them by trying to entice them with nondonation-related benefits. Why risk the possible negative stigma associated with financial incentives if the country with the highest per million rate of living organ donation in the world has achieved that status without them?

CONCLUSION

The risk of death is real for the 117,000 Americans waiting for transplants, but the medical and financial risks to living organ donors are also real. When asking a healthy part of the population to sacrifice to help those in need of organs, the right approach is to find out what organ donors need to make an informed choice easier, not to focus on what might tempt an uninformed public to donate. The most ethical approach is to treat living organ donors with the dignity and respect they deserve, even if doing so does not increase the number of donations. I struggled to find an ethical middle ground when I returned from Iran. But now that the Netherlands is outperforming Iran in its living organ donor program, there is no reason to consider taking anything but the ethical high road and giving living organ donors what they say they need—and nothing more.

About the Author

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13. https://www.transplantatiestichting.nl/cijfers/organen-jaarcijfers/orgaandonatie-van-een-levende-donor. Accessed October 13, 2017. The tables indicate that 42% of all donors are related by blood (specifically: mother, father, child, sibling, grandparent, aunt or uncle, and nephew or niece), and 30% by marriage or other family relation not included in the 42% category.

"But It's a Gift!" Adherence Pressures Post-Transplant

Laura Guidry-Grimes, PhD

"Gift" language is rampant in public campaigns, scholarly studies, and analyses, and even in the hallways of hospitals when referring to transplantable organs. The organ-as-a-gift notion brings with it a number of social and moral implications, not only for motivating potential donors and their families, but also for motivating recipients. In a review article of determinants of non-adherence among transplant recipients, the authors conclude:

> Because of an ever increasing number of patients waiting for organ transplantation, it is incumbent upon physicians, patients, and family members and social support groups to realise that the "precious gift" that has been bestowed upon the transplant recipient must be cherished and nurtured with great care.[1]

In a study of predictors of non-adherence, the authors emphasize that "society bears the costs of mishandling the 'gift of life' in terms of graft loss, dialysis therapy, retransplantations, and wasted resources."[2] A pharmaceutical periodical makes a number of evocative points:

> "As a transplant recipient, you have been given a second chance at life through the selfless donation of another. An important way to hone, appreciate, and protect that gift of life is to comply with your health team's medical instructions. Through compliance, you take good care of your transplanted organ and yourself, making the most of your precious second chance at life."[3]

These citations indicate a particular attitude and judgment: Transplant recipients are *morally obligated* to be as adherent as possible out of respect for the "gift" given to them; along the same lines, non-adherence is a particular type of *moral failure*.

The "gift ethic" in transplant contexts needs further analysis, especially given how "gift" language can structure moral relationships among donors, donors' families, healthcare professionals (HCPs), organ procurement coordinators, prospective and past transplant recipients, and recipients' support systems. Although substantial literature explores the gift ethic as it relates to encouraging donation, there are far fewer studies and discussions on how this ethic impacts recipients. This issue merits investigation because transplant recipients are frequently subjected to moral remonstrations and various other pressures to respect their "gift," but to what extent these pressures are justified is not always evident or obvious. Depending on how the gift ethic operates in healthcare professionals' relationships to transplant recipients, it can lead to uncharitable and punitive stances toward non-adherent patients, and it can seemingly justify aggressive techniques to try to

"improve" these patients' behavior. My aim in this paper is twofold. First, I will briefly analyze how organs could be a certain type of gift.[4] Second, I will investigate the general moral obligations and justifiable expectations of organ recipients as implied by the gift ethic, and I will outline the limitations of those obligations and expectations.

ORGANS AS GIFTS

Paradigmatically, gifting occurs when an agent gives something knowingly, voluntarily, and intentionally with the purpose of benefiting the recipient without explicit or implicit expectation of compensation in return.[5] When an agent gives a gift with implicit or explicit (noncompensatory) expectations of what the recipient ought to do in response to receiving the benefit, there are strings attached to the gift. These strings normally arise from mutual agreement between the gift giver and the recipient. The strings can be weak or strong, depending on what expectations the gift giver has. When gifts have strong strings attached, demanding return of the gift, reimbursement, or an apology would be justified if the recipient does not do as expected. For instance, imagine Susan gives her daughter a $100 gift card to congratulate her on straight As on her report card, but she learns that her daughter forged her report card in order to get the reward. Susan could justifiably demand that the money be returned—the daughter would be mistaken to insist on keeping the money because "it's a gift." A number of factors and competing norms can affect whether the giver actually tries to get the gift back from the recipient (for example, not wanting to strain the relationship, infeasibility of returning the gift); nonetheless, when gifts have these strong strings attached, the giver is justified in deeming it a sort of injustice and at least demanding an apology.[6] Importantly, whenever someone gives a strings-attached gift, the strength and nature of those strings should be as clear and explicit as possible within mutual agreement; otherwise, the gift recipient is more likely to fail the moral expectations of the giver, and the recipient would have mitigated blame (if any blame) for this failure.

When organs are gifts, they have strings attached. In cases of living donors designating organs for particular recipients, the living donors might have any number of expectations of the recipients, based on their relationship and how the donors hope the recipients will live out their life in response to getting a "second chance." Donors who arrange posthumous donation will likely have fewer and less specific expectations, given that they have no knowledge of who could receive their organs. There is at least one expectation tied to every instance of organ donation[7]—that the organ will *benefit* the recipient. Presumably, no one would participate in the donation system at all if the organs did not tend to contribute positively to the lives of recipients; the sustainability of the system depends on this expectation being met more often than not. Numerous factors determine how effective a transplant will be in benefiting the recipient, and these factors can vary significantly in how obvious or occluded, controllable or intractable, predictable or capricious they are. Whenever it seems that a recipient's decision could make the difference for the survival of the organ, donors, HCPs, procurement organizations, patients who remain on the wait list, and families can have expectations[8] of the recipient.

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In order to be eligible for an organ, potential recipients have to prove their commitment to their own healthcare by keeping appointments, participating in healthcare discussions, and following a medical regimen. This pre-transplant period of waiting for an organ and proving one's commitment can last from days to years. After receipt of an organ, recipients are expected to continue their commitment, which includes strictly adhering to medications, communicating any health problems to HCPs, agreeing to readmission as needed,

agreeing to long convalescences if needed, making recommended diet and lifestyle changes, and consenting to any additional medically necessary procedures. The strings attached to these gifts thus stretch into many aspects of daily living, including intimate and personal decisions.

When HCPs believe they have an obligation to uphold the gift ethic, they take on the responsibility for ensuring that transplant recipients respect the strings-attached nature of their "gift." The end result is that HCPs could seem to be justified in demanding a great deal from transplant recipients—that the gift ethic even compels them to make sure that recipients abide by the moral expectations that come with acceptance of the donated organ. When HCPs view their role in the gift ethic this way, they are claiming significant moral authority. This moral authority includes knowledge of how transplant recipients should conduct their lives, what healthcare decisions are morally appropriate, and what pressures should be exerted by HCPs to attempt to influence recipients' behavior when they fail to be adherent. As with all presumed or actual authority, we need to determine its limits.

MORAL LIMITS TO ADHERENCE PRESSURES

When a transplant recipient presents with some signs of non-adherence, it is within the professional purview of HCPs to investigate the extent of the non-adherence and possible causes, which could involve tests and a series of personal questions. It is also within their purview to try to address any obstacles to adherence, since strict adherence to immunosuppressant medications and other aspects of a medical regimen is necessary for the success of the transplant.[9] Truly, it is more than "within their purview"—these steps are fundamental to the role of HCPs and the therapeutic relationship they must try to build with patients. The trickiness comes in trying to discern how much is too much, for questioning can become interrogating or badgering, and addressing obstacles to adherence can turn into a host of problematic tactics. It can be distressing for HCPs whenever patients make decisions that seem suboptimal for their health, but the gift ethic adds another dimension of distress for HCPs: according to this ethic, non-adherent transplant recipients are failing important moral obligations to others, not just to themselves.

If HCPs are concerned that patients will not choose to be adherent for any number of reasons, then there is a range of interventions that HCPs might attempt, formally and informally, intentionally and unwittingly. For example, HCPs can end up shaming patients for not taking all of their medication or for missing appointments, which can appear to HCPs to be "easy" ways for patients to show their gratitude for their so-called gift. Shaming can even creep into conversations about the recipients' expressed thoughts and feelings about the organ. In a study of the phenomenological aspects of being a transplant recipient, it was reported that "when meeting medical staff and complaining about their anxiety and fear of the unknown and new life situation, some female respondents experienced attitudes of negligence and demands on expressing gratitude instead of complaints."[10] To shame a patient is to blame them, to suggest that the patient simply needs to choose to have increased commitment and willpower. Shaming also expresses a kind of *disappointment*, which can have a lot of force in transplant relationships built around the gift ethic.

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In addition to shaming, some other tactics could include paternalistic measures, shading the truth, and even coercive pressure. For example, a physician could give overly optimistic projections about how long the transplant recipient will need to remain hospitalized in order to decrease the chances that the patient tries to leave AMA (against medical advice). The medical team could likewise minimize the negative side effects of medications, emphasize favorable statistics over those that are

less favorable, and prod family members to make appeals for improved adherence. In cases of extended non-adherence, patients are more likely to be viewed as "difficult," leading to a ruptured therapeutic alliance with current and future medical teams.[11] Some physicians in these situations might even convey to the patient that they will not be able to continue on his or her case if the patient's behavior does not change; this tactic could be viewed as coercive by the patient, depending on whether the patient values the relationship. All of these tactics can be well-intentioned; HCPs might not even recognize these pressures as potentially problematic, particularly if their impression is that the transplant recipient shares a commitment to the gift ethic. Based on this line of reasoning, trying to improve adherence is thus beneficial for patients' medical well-being *and* for their integrity.

All of these strategies warrant their own ethical analysis. I will focus on an initial ethical issue that has to be addressed: Whether there is a limit to the moral obligations that transplant recipients have to protect their organ, thus showing respect for their so-called gift. If there is no limit, then repeated (and perhaps even aggressive) remonstrations and tactics could be justified in order to help the patient do right by all of those in the gifting relationship. If there are limits to recipients' moral obligations, though, then that suggests HCPs should, at some point, stop pressuring these patients to conform with their notion of an ideal transplant recipient. If there are limits, then a non-adherent transplant recipient is not always a moral failure. I contend that there are indeed limits to these moral obligations, and I outline four circumstances in which non-adherent transplant recipients should not be viewed as moral failures.

When Expectations Were Not Clear

One circumstance that mitigates the moral responsibility of non-adherent transplant recipients probably occurs rather frequently: The recipient did not sufficiently understand or appreciate the requirements for maintaining the organ's survival. As mentioned previously, the strings of a strings-attached gift should be as clear and explicit as possible with mutual agreement. This means that prior to acceptance of the "gift," would-be transplant recipients need to grasp the expected post-operative course, possible complications, the possible need for future hospitalizations, the medical regimen, and what all of this means for their life. Achieving this level of understanding and appreciation is difficult for any patient, and successfully communicating all of these details and possibilities is nearly impossible for any physician. The life-or-death desperate nature of being on an organ wait list can make it even more challenging for patients to comprehend the negative impact that a donated organ could cause for their life. In the same vein, any informed consent conversation will fail to convey all of the relevant details of a patient's lifelong post-transplant regimen, especially since the regimen will likely change over time and depend on specifics of a patient's body and lifestyle. Even if the informed consent process was as successful as possible pretransplant, there are arguably aspects of the medical regimen that can only be learned through experience. For example, experience will reveal how the medication affects daily living and how inconvenient the regimen is. Given these substantial impediments to the informed consent process, many patients can justifiably claim that they did not really know what they were agreeing to in accepting the "gift."

When External Barriers Are Significant

There is another common circumstance in which non-adherent transplant recipients are not moral failures: when external barriers make adherence immensely burdensome. Medications, any special diet, clinic visits, and transportation can become financially onerous, for example. Patients can lose easy access to healthcare resources without easy solutions to improve access, such as when they lose insurance coverage or family support. Multiple studies report that well-intentioned patients struggle with their dosing schedule and other upheavals to their daily living. The medications can have significant side-effects as well, including problems with weight, moodiness, lethargy, skin problems, inability to fight infection, swollen gums, joint pain, hair growth, and shakiness. Especially while living under the gift ethic, patients often experience enormous guilt when any of these obstacles decrease their adherence.[12] Undesirable complications and side-effects might not be treatable, and patients could understandably refrain from mentioning them if they expect to be admonished for not being grateful enough for the organ. As a result, these external barriers can be long-standing and worsen over time, and HCPs will rarely have complete knowledge of what these barriers are, especially when HCPs reinforce the gift ethic in their encounters with transplant recipients.

When Internal Barriers Are Significant

In addition to the external barriers mentioned above, transplant recipients are often overwhelmed by internal barriers. Maintaining the commitment to a donated organ requires hope, resilience, and confidence. The entire painful, terrifying, and uncertain experience of having that organ—especially in an alien environment surrounded by strangers insisting that they be trusted—can deplete mental and emotional reserves. Transplant recipients frequently experience loss of control, helplessness, and loss of independence when in the hospital.[13] Rejection episodes take a profound physical and emotional toll on patients as well, and, in one study, "none of the patients who were frustrated, had depressive thoughts, felt defeated or were afraid of dying, said anything about having received help, comfort or support from the health personnel."[13] When these negative emotional attitudes are correlated with decreased adherence, it would be reductionistic and uncharitable to call these difficulties mere *akrasia* (a lack of self-control or willpower). It takes time to build the necessary coping strategies, but patients will often experience more complications, hospitalizations, and problematic encounters with HCPs over time as well. All of these negative experiences can feed into feelings of helplessness. Even when patients are adherent, many of them will have these negative experiences in any case, perpetuating a lost sense of self-efficacy. Studies report that a "sense of self-efficacy acts as a protective factor in stress, allowing a more positive and functional coping behavior" throughout the long-term care of transplant recipients.[14] Removing complex psychological barriers and gaining a sense of self-efficacy require more than willpower. These internal obstacles can be largely outside the control of the patient, especially given the general dependence of patients on HCPs and other social supports.

When Healthcare Goals Evolve

There is a fourth notable circumstance in which non-adherent patients should not be viewed as moral failures, even under the gift ethic. Transplant recipients should be "let off the moral hook" regarding protection of their donated organ if, after reasonable attempts to be adherent, they make a reasoned and reflective decision not to follow the medical regimen any longer, in full or in part. If the patient accepted an organ without expecting to be adherent, or if the patient did not make a reasonable attempt to be adherent, then we could justifiably find moral fault with the patient's decisions. The gift ethic should compel recipients to *try* to abide by the expectations attached to the transplant, but these strings cannot bind a recipient absolutely. The point of organ donation is to help a *person* live a better life; the point is not merely the survival of an organ for its own sake. This point may seem obvious, but the dark side of the gift ethic is that a recipient's own valuing of the transplant can become quickly lost. The moral assumption appears to be that a recipient values a "second chance" more than anything and is willing to make all necessary sacrifices to maintain the health of the organ. Even if a recipient does not explicitly say anything along these lines, it can be tempting to regard this sort of valuing system as the most rational one, since otherwise the patient in organ failure will presumably die. While HCPs might believe that they are protecting what the patient "really" wants by encouraging adherence through any of the strategies described above, they are neglecting to consider the experiential knowledge gained by the patient and how that knowledge can cause preferences to evolve.

Transplant recipients should be "let off the moral hook" regarding protection of their donated organ if, after reasonable attempts to be adherent, they make a reasoned and reflective decision not to follow the medical regimen any longer, in full or in part.

If a patient decides that living with the transplant is not worth it, after he or she learns the costs and benefits more intimately, then the patient's decision has moral merit. By choosing not to follow

the medical regimen any longer, the patient could be standing up for newly developed healthcare goals that are more informed, reasoned, and authentic. HCPs should encourage self-advocacy, not self-abnegation. The organ donation system would likely fall apart if transplant recipients were explicitly *demanded* to maintain their organ, regardless of how their values and preferences changed over time. Imagine a different gift example: A financial donor creates a competitive scholarship program for students who express a serious interest in the medical profession, and this scholarship is in the form of a single lump of money dispersed during the first semester of college after enrolling in at least one pre-med course. Without this funding, Justine would not be able to afford her first year of college, so she eagerly accepts when she wins the scholarship. As it turns out, Justine loses interest in medicine during the pre-med course and plans on changing career paths, but she has already spent the funds on necessary expenses. Has she failed her moral obligations to the donor, other students who did not receive the award, and all of those who helped make receipt of the scholarship possible? If Justine never had a serious interest in medicine, then she could be blameworthy for applying for the scholarship. If she changed her mind about what she wants for her life after thoughtful deliberation and experience with the pre-med track, then she should not be viewed as a moral failure. In giving a freshman a scholarship for a particular career path, the donor is making a gamble that the beneficiary will have the same professional goal over the years, but this gamble is *understood*. In this scholarship example, as in organ donation examples, the donation system accepts such a gamble as part of what it means to give to persons (instead of, say, institutions under a binding contract). The donation system cannot justifiably demand that beneficiaries bind their autonomy forever.

CONCLUSION

I have offered a nuanced analysis of the gift ethic and its limits in transplantation. The gift ethic fortifies the "sick role" of transplant recipients, framing them as lifelong patients who should forever be grateful that they were given a chance of survival with proper healthcare monitoring and compliance. To the extent that organs can be viewed as "gifts," they are gifts with strings attached, and HCPs can make critical moral errors when they misunderstand the nature of those strings. While HCPs should try to investigate and address problems of non-adherence, they do not have total moral authority to judge and persuade these patients. Depending on the details of the case, it may be that certain persuasive techniques are more ethically justifiable immediately after the transplant than they are later on in the process. Even under the gift ethic, however, there are limits to the moral obligations of transplant recipients to be adherent.

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4. Those who believe organ donation is morally *obligatory* will disagree that organs can ever be properly conceptualized as gifts (since gifting is, by its nature, supererogatory). D. Micah Hester makes this type of argument in "Why We Must Leave Our Organs to Others." The philosophical debate on this point is outside the scope of this paper, as I am unpacking the more common notion that organ donation is a type of gifting, and there are arguments for keeping the gift ethic despite its limitations (see Murray). Hester DM. "Why We Must Leave Our Organs to Others." *AJOB.* 2006;6(4):W23-W28. Murray TH. "Are We Morally Obligated to Make Gifts of Our Bodies?" *Health Matrix.* 1991;19:19-29.

5. If this definition is correct, then it would be relatively rare for organs to be true gifts, but I do not have the space in this paper to provide that argument.

6. Alida Liberman argues that the gift ethic cannot ap-

ply to organ transplantation because it "predicts that the donor as giver is not permitted to unilaterally revoke the gift and thereby regain ownership of her organs," but donors can change their mind about being donors. For the reasons I give in this section, I disagree with Liberman's assertion that gift revocations are impossible, though I do not believe organs-as-gifts have these strongest strings attached to them. I agree that donors should be permitted to change their mind about donation *before* donation occurs, but it seems uncontroversially unethical for a donor (or family on a donor's behalf) to try to change their mind *after* the donation occurs (a situation that Liberman does not consider). Liberman A. "A Promise Acceptance Model of Organ Donation." *Soc Theory Prac.* 2015;41(1):131-148.

7. This explicit expectation is at least had by HCPs who arrange the transplant, and these professionals could be viewed as working on behalf of the organ donor's presumed intentions as a gift giver.

8. While some of these individuals will have face-to-face interactions with the recipient and can express their expectations more directly, others will not. The gift ethic can nonetheless be perpetuated by those who never meet recipients, such as when families contribute their time and money volunteering for donation campaigns that emphasize the "gift of life" or when representatives of procurement organizations are invited to participate in hospital policy discussions about non-adherent transplant recipients.

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Post-Transplantation Palliative Care: Misconceptions and Disincentives

Michael J. Pottash, MD, MPH

Over half a century ago, the first whole-organ transplantation upended what was expected for patients with advancing illness. As surgical transplant techniques improved, immunosuppressive therapies grew more sophisticated, and organ transplantation became commonplace, the aim of medical therapy shifted from management and acceptance to cure and survival.

Despite the success of organ transplantation, transplant recipients continue to have significant healthcare needs. Perioperative complications, intensive care unit stays, family distress, and burdensome symptoms[1,2] are only some of the reasons why transplant recipients may benefit from palliative care services even after transplantation.[3] However, two major barriers interact to impede the routine integration of palliative care services for these patients: Misconceptions about the goals of palliative care and the quality care outcome measures that have the unintended consequence of disincentivizing its routine use.

The promise of organ transplantation is one of survival. Take liver transplantation as an example: Those with end-stage liver disease who receive a transplant now have a greater than 60% survival rate at 10 years.[4] This dramatic turn tends to shade the reality that persists even after successful transplantation. First, patients with one failing organ tend to have other health concerns that remain after transplantation. In one study, 90% of kidney transplant recipients had a comorbidity.[5] Second, living with a transplanted organ constitutes its own chronic illness, requiring frequent interactions with the healthcare system, immunosuppression, and an oppressive pill burden. Additionally, they have a new status within the healthcare system as organ recipients. They need support and attention as they navigate this new identity. Third, recipients and their families tend to have a significant number of physical and psychological symptoms.[1,2] The psychological impact of living and coping with a serious illness does not disappear with transplantation; it continues to have a significant effect on well-being.

Palliative care is meant to provide for patients who experience the psychological and physical symptoms of advanced illness, and transplant recipients may benefit from such services. Over a decade ago, the American College of Surgeons published a position statement on palliative care:

> If palliation is taken to apply solely to care near the time of death, or "comfort measures only," it fails to include the life-affirming quality of active, symptomatic efforts to relieve the pain and suffering of individuals with chronic illness and injury.[6]

Since then, there has been a growing body of literature on the benefits of palliative care services

for transplant recipients. Take, for example, a study of transplant recipients receiving palliative care services in the intensive care unit (ICU), regardless of prognosis. These patients had closer attention paid to their pain and other symptoms, their specific goals of care, and elements of their shared decision making, resulting in increased discussion around those goals, earlier institution of a do-not-resuscitate (DNR) order, decreased hospital length of stay, and increased withdrawal of aggressive medical therapies.[4] Integration of palliative care services into the workflow of the ICU improved symptom control, communication, and dying care, aspects of ICU care that are meaningful to patients and their families. All of these benefits were conferred with no difference in overall mortality when compared to the standard care group.

Surgical associations have noticed the evidence reporting that palliative care services benefit transplant recipients. In an essay published last year in the official newspaper of the American College of Surgeons, the authors stated,

> Any patient awaiting transplantation, any patient's family considering organ donation from a critically ill loved one, and any transplant patient with chronic organ rejection or other significant morbidity is appropriate for palliative care services. Palliative care support addresses two needs critically important for successful transplantation outcomes: Improved medical compliance that comes with diligent symptom control and psychosocial support.[7]

The author of this essay believes that the time has come to consider palliative care services for transplant recipients as the standard of care.

Meanwhile, transplant medicine, as a surgical subspecialty, has been slow to consistently integrate palliative care services. In one survey of 18 large transplant centers, 10 had involved palliative care for less than five patients in the previous year, while seven of the centers had involved palliative care for less than two patients; no transplant center had criteria for routinely assessing the palliative needs of transplant recipients or their families.[8] In the same survey, the authors asked the surgeons to explain why palliative care services continue to be underused for patients with significant palliative needs. The transplant surgeons cited uncertainty regarding prognosis, the perception that palliative care precludes aggressive treatment, and concerns over discussing palliative care with transplant recipients and their families as barriers to more consistent palliative care. The majority of the surgeons still associated palliative care with "end-of-life" care. However, in the same survey, the surgeons overwhelmingly endorsed the idea of integrating palliative care services into post-transplant clinical management.

The results of this study present an odd cognitive dissonance: The belief that something is simultaneously useful and yet not useful. When asked, surgeons want their patients to have routine access to palliative care services and, at the same time, feel that involving a palliative care practitioner is often not appropriate based on prognosis or current treatment plan. It is tempting to blame gaps in knowledge, the expectation of survival after transplantation, or even a "surgical culture that emphasizes salvation of life, regardless of context or consequence."[9] Perhaps the story is even more complex.

For many medical interventions, the mortality rate has long been the most popular outcome measure in the movement to improve quality care, serving as a reminder that clinical decisions can have perilous consequences. Collecting and publicly reporting mortality rates is meant to provide patients, referring physicians, and insurers with the information that they need to select clinicians, and to give clinicians an incentive to improve and deliver high-quality care. Despite these admirable goals, reporting the mortality rate may have unintended consequences on clinicians' behavior.

One such consequence of publicly reporting the mortality rate is that clinicians may avoid providing a beneficial intervention to higher risk patients even though the data are adjusted for severity of illness.[10] One study compared the rates at which clinicians performed a therapeutic intervention for patients having an acute myocardial infarction (MI), a heart attack, between states that publicly reported a 30-day mortality rate for the procedure and those that did not. Patients with an acute MI in states that publicly reported their outcomes were less likely to receive the intervention than similar patients in nonreporting states.[11] Most striking, when Massachusetts began publicly reporting during the study period, the rates at which its clinicians performed the intervention significantly dropped to those commensurate with rates seen in other reporting states. The authors concluded that when faced with the prospect of having their 30-day mortality rates publicized, clinicians began avoiding patients they perceived as being at higher risk, even when risk adjustments are made.

Another group surveyed interventional cardiologists to ask whether their clinical behavior was influenced by public reporting. The vast majority of cardiologists agreed that even though severity of illness is taken into account, public reporting of their 30-day mortality rates increased their reluctance to intervene in cases of high-risk patients who may benefit from intervention.[12] Under the shadow of a reported mortality rate, at the population level and in self-report, clinicians are turning away sicker patients who may benefit from an aggressive intervention.

Furthermore, there are certain surgical interventions that are performed to improve quality of life in patients with an advanced illness. These may be risky procedures with a high chance of mortality in the perioperative period. Nevertheless, many patients may prefer to accept the risk in order to attain relief from the burdensome symptoms of an advanced illness. Reporting the mortality rate disincentivizes clinicians from performing palliative interventions, forcing them to choose between providing these patients with a potentially life-improving procedure or abandoning them in order to preserve their mortality rate.

The mortality rate may also influence the way that clinicians care for their patients who experience a complication or clinical decline in the postoperative period. Pressure to exceed the mortality rate can artificially bolster a clinician's natural optimism and disincentivize a clinician from having frank discussions with patients or their families.[13] If clinicians believe that palliative care is strictly end-of-life care, or that it precludes aggressive medical therapy, then these patients will also be less likely to receive expert palliation of physical and psychological symptoms.

The unintended consequence of collecting and publicizing mortality rates raises the question of how we are to define quality of care in medicine. Do we measure quality only in clinical terms like survival? Or should we also account for a patient's function, as in whether the intervention has improved the patient's life? While prolonging life is one way of defining quality medical care, should it be coveted at the exclusion of the many other ways in which people define quality?

The effect that the mortality rate has on decision making in the field of transplant medicine may be even more insidious. The condition for transplant centers to receive Medicare certification and reimbursement depends on two metrics: One-year post-transplant patient survival (a mortality rate) and one-year graft survival. The Centers for Medicare & Medicaid Services (CMS) collects these metrics in an effort to improve patient safety and transplant outcomes. Commercial insurers then piggyback on these metrics to qualify programs for Centers of Excellence status and determine network eligibility.[14] Transplant centers that are cited by CMS for poor outcome metrics can see a drop in their referral volume, resulting in fewer transplant cases and decreased hospital revenue.[15] Since the volume of organs transplanted at an average institution is modest,[8] even a single death within a year of transplantation can adversely affect the way that a transplant center is reimbursed or rated, and even impact its ability to transplant organs.

Is it any wonder that transplant surgeons and transplant center administrators pay close attention to one-year post-transplant patient survival? In a concept paper on behalf of the United Network for Organ Sharing and the Organ Procurement and Transplantation Network, the transplant community expressed its concern that surgeons avoid transplanting kidneys from high-risk donors because of the perception that risk-adjusted models for metric

Reporting the mortality rate disincentivizes clinicians from performing palliative interventions, forcing them to choose between providing these patients with a potentially life-improving procedure or abandoning them in order to preserve their mortality rate.

collection are inadequate to buffer against poor outcomes.[16] The American Society of Transplant Surgeons published an article, *Transplant Center Outcome Requirements—A Threat to Innovation*, in which it suggests that the current metrics, even with risk-adjustment, stymie transplantation innovation if transplant surgeons fear that their transplant center may come under review.[17] In addition to being concerned for the well-being of their patients, they are understandably vested in the survival of their transplant programs. Transplant surgeons know that their efforts to heal critically ill patients will be hindered if their transplant center has poor ratings, has an imperiled revenue stream, or has no access to incoming organs.

If statements by the societies and networks that represent transplant medicine and advocate for transplant recipients are taken to suggest that the one-year post-transplant metric leads transplant surgeons to avoid certain patients, then it is also likely that, as with the 30-day mortality rate, it creates a strong incentive to keep their patients alive past the one-year mark. And like the 30-day mortality rate, it is reasonable to expect one-year post-transplant survival will act as a strong disincentive to routinely integrate palliative care services for their transplant recipients. After all, the study described previously, which engaged palliative care for transplant recipients in the ICU, can be interpreted as a list of outcomes: increases in discussions around goals of care, earlier institution of DNR orders, decreases in length of stay in the surgical ICU, and increases in the withholding or withdrawing of life support.[4] To many clinicians, these outcomes are synonymous with "giving up." Is it really surprising that many transplant surgeons still equate palliative care with "end-of-life" care and believe that they and palliative care practitioners have contradictory goals?[8]

The implication that one-year post-transplant survival has a chilling effect on routine integration of palliative care services for transplant recipients is alarming, given the evidence that palliative care services provide transplant recipients with much-needed benefits. It is unsettling that in an effort to improve the care for patients receiving the lifesaving intervention of organ transplantation, we may be curbing their access to expert palliative care.

Despite the impressive gains accomplished in the field of transplant medicine, transplant recipients continue to have significant physical and psychological symptoms after transplantation. Palliative care services provide these patients with considerable palliation and support, without an increase in overall mortality. Although palliative care champions have spent the last several decades educating the transplant community, misconceptions about the role and purpose of palliative care services continue to be a barrier to their routine integration. Misconception leads to hesitation, as the one-year post-transplant patient survival metric, like the 30-day mortality rate, creates a strong incentive for transplant surgeons to recommend quantity over quality of life. Champions of palliative care must continue to dialogue with their colleagues in transplant medicine, and to accumulate evidence to support innovative models for providing transplant recipients with palliative care services. Meanwhile, it is time to reconsider how we measure quality in medicine and to eliminate metrics that disincentivize routinely integrating palliative care services into the care of transplant recipients.

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Teaching Clinical Ethics Through a Mock Hospital Ethics Committee

Thalia Arawi, PhD, and Maya Hajj Hassan, BS

GOOD CLINICAL CARE REQUIRES A SENSITIVITY TO ETHICS

Ethical dilemmas occur frequently throughout the practice of medicine. Moral questions about patients' incapacity, overtreatment in some cases and undertreatment in others, resource allocation, and many others are commonplace for doctors, regardless of specialization.[1] As medical technology develops at an unprecedented pace and people are becoming more aware of their rights as patients and more in need of shared decision making, problematic management of moral dilemmas can, and often does, lead to unhappy physicians and patients/families. Moral conundrums that are not well addressed lead to dissatisfied patients and families, as well as discontented physicians, malpractice lawsuits, loss of medical licenses, and possibly even jail time for physicians. Accountability and transparency are an integral part of hospital policies. However, clinical ethics is more than an issue of litigiousness, legalism, and avoiding liability. It is also about the respect, responsibility, and duty owed to patients and their loved ones. In any case, we have reached a time when there is no questioning the need for clinical ethics or its benefits for healthcare in terms of hospital accountability, physicians' moral standing, or patient safety.

Teaching clinical ethics to future physicians and allowing them to realize its importance, however, is quite challenging and less clear cut, precisely because the general misconception is that bioethics is an intruder to the profession of medicine. So when should medical students begin learning clinical ethics and how do medical schools best go about teaching it to them? The most disseminated methods for teaching clinical ethics are lectures, case studies, symposia, seminars, and small group discussions among students.[2] However, a classroom setting presents challenges for educators in conveying the complexity of moral issues to medical students.[3] In addition, teaching through case vignettes and lectures does not do justice to the complexities and particulars of the issues that lurk behind the cases of individual patients. Indeed, despite the importance of ethics in the practice of medicine, students seldom get the chance to apply the medical ethics principles they learn.[2] In order to allow students to appreciate clinical ethics, the Salim El-Hoss Bioethics and Professionalism Program (SHBPP) at the American University of Beirut Faculty of Medicine launched one module in clinical ethics (part of the Physicians, Patients, and Society—PPS—2 course), which culminates with medical students partaking in a mock hospital ethics committee. Surveys report a desire among medical students for more "integrated exposure" of medical ethics throughout the medical curriculum.[4]

PPS1 AND PPS2: WHAT HAVE MEDICAL STUDENTS LEARNED SO FAR?

The Physicians, Patients, and Society (PPS) sequence courses offered to medical students at the American University of Beirut Faculty of Medicine (AUBFM) aim to teach students medical ethics in the most comprehensive manner possible. Not unlike most medical education, the trend at AUBFM is to go from the general to the specific, from the theoretical to the applied. As such, the first course of the PPS sequence, PPS1, teaches students about art, literature, and history. In their first year, students gain an understanding of human emotion and the human experience by learning about the humanities and their relation to the medical discipline. They learn to understand the complexity of human persons and their multidimensional layers. Thus, students appreciate that patients who have the same disease are unique individuals living in society, with their own particulars and variables, which will affect the patient-centered care given to each unique patient. PPS 2 delves more into specific patient issues that arise during patient care, and includes modules on palliative care and the whole patient, spirituality in medicine, nurse-physician relationships and their effects on patient care, and an introduction to clinical ethics.

In their first year, students gain an understanding of human emotion and the human experience by learning about the humanities and their relation to the medical discipline.

MOCK MCEC

The culmination of the clinical ethics module is a mock Medical Center Ethics Committee (MCEC), as it is called at our institution, much like the actual MCEC that serves as an advisory board at the American University of Beirut Medical Center (AUBMC). Prior to partaking in the mock MCEC, students have sessions on philosophical bioethics, the four-box method to enhance ethical decision making,[5] as well as clinical ethics and patient care. The program has taken place for three years, with over 300 medical students participating in the module and integrating it into their understanding of clinical ethics. This mock MCEC replicates the actual MCEC as closely as possible. It takes place in the same room, the medical conference room. Students are treated like real members of the MCEC and are sent an email informing them of the agenda for the meeting, as well its time and place. Before the mock committee takes place, students are assigned two cases and instructed to read them carefully. Each student is then assigned a role in the mock MCEC, which he or she will assume during the committee meeting. The MCEC is composed of physicians, community members, social workers, psychiatrists, religious figures (from different faiths), and lawyers. The roles are assigned by the course coordinator to ensure that students will get the most out of the learning experience; the students are assigned a different role for each case. As preparation, prior to the session, students read the *Lebanese Code of Medical Ethics*[6] and related articles that allow them to assume their roles. The students are then required to submit a written report on Moodle, an online learning portal used by the medical school. Students are seated in their assigned seats in the conference room, breakfast is served (an assortment of pastries, brownies, and coffee), and the meeting begins. These formalities are in place to add a dimension of realism to the mock MCEC. Subsequently, students get a feel for what the MCEC is really like and take their roles as members more seriously than if they felt this was a classroom activity.

The mock committee, chaired by a clinical ethicist and the vice chair of the MCEC, commences with the introduction of the case by the student who has the role of the attending physician. Various points of view are discussed in light of each student's assigned role—that is, a lawyer would discuss the legal aspects of the case, a psychiatrist the mental health aspects, a risk-management specialist the risks, a priest shares the theological view of the church, a Sheikh shares the Islamic Jurisprudence view, and so on. It is important to note that Lebanon is a country where religion plays

an important part in ethical decision making, and indeed many clinical ethics cases have at their roots a religious tension. When roles in the ethics committee are assigned, Muslim students are given the role of the priest and Christian students are assigned the role of the sheikh. In this way, students are given the chance to examine issues from perspectives different from their own, and the mock MCEC can be considered an exercise in empathy, as it places students in positions from which they have to argue a viewpoint that may not particularly be their own. Allowing students to examine ethical issues from different perspectives serves to engage their critical thinking even further, as they strive to grasp the situation from another point of view. They also learn that shared decision making from multiple backgrounds leads to the best patient outcomes. As the exercise continues, students forget that they are playing a role and start arguing vehemently, trying to reach what they think is in the best interest of the patient. They genuinely feel they have a stake in the meeting, and want to reach the right moral recommendation. The discussion achieves a depth that would ordinarily not be possible in the classroom, and students are able to experience the tangibility of the patient's case. Although they start hesitantly, they eventually assume their roles and start using their *phronesis* (practical wisdom) when they debate an issue or concept. Most importantly, often they find their preconceived notions being challenged in a healthy and safe environment, and they often challenge their own preconceived notions in the face of new evidence or arguments. Thus, their experiences are enriched. This exercise allows the instructor to assume the role of the "Socratic gadfly," who stings students out of complacency and awakens them from their dogmatic slumber—in which they might otherwise simply recite the normative ethical principles they already know—and encourages them to consider the practical implications of the ethical decisions they make and their effect on their patient, the hospital, and society as a whole.

In the process, several practical questions regarding ethical decision making arise. What happens if this is a time-sensitive issue? If the patient is unconscious or incapacitated and the surrogates are at odds with the hospital staff, what happens next? What is the precedent on patient autonomy versus their ability to make decisions for themselves when they are in pain? In examining the issues for themselves, students begin to see the complexity and depth of moral decision making, and, being unpracticed in clinical ethics themselves, they begin to have questions to which they are eager to find answers.

Other practical aspects come to life in this exercise, further enriching the dialogue. Students are forced to examine the patient population of their region and appreciate the importance of cultural issues when it comes to patient care. They come to appreciate that sometimes although applying the law is paramount, an additional ethical safeguard is necessary, since at times one might face situations where what is legal is unethical and what is ethical is illegal.

At the end of the two-hour session, recommendations for each of the cases are given; motions are raised and approved, and recommendations reached. In each case, the two members playing the role of secretary (who are assigned upon request and assume other roles they have chosen during the mock MCEC) send the minutes of the meeting on the same day. The cases presented to the mock MCEC are real cases that have been considered by the MCEC, allowing the chair of the meeting to share with the students the outcome of the deliberations and the recommendations of the real MCEC. Students are always happy to learn that they reached the same conclusion, and, interestingly, although not surprisingly, with more in-depth discussion, as they approach the subject backed by ethics education, and with the enthusiasm and freshness that is characteristic of students in medical school. During the actual MCEC, the recommendations of the students are shared with members. This often leads to discussions and more pondering. Finally, the students receive a copy of their minutes and the session is officially closed.

The mock MCEC exercise is successful for several reasons. Playing the roles of different professionals who are engaged in discussion about a complex patient case gives students a venue to be engaged in a serious and dedicated manner that is unique. Students navigate through the case discussing particulars and variables that might have gone unnoticed outside the session. It gives them a chance to understand the direct bearing of the relevant considerations (social, legal, religious, financial, medical, and so forth) on the case, and the impact these have in shaping the recommendations. They appreciate that the role of the ethics committee is more complex and pivotal than they had initially thought and come to understand that clinical ethics is often at the heart of actually providing patient-centered care. Most importantly, they end up appreciating how complex a patient is

and how unfair it is to treat a patient as an illness, and assume that the patient has been cured when the psychosocial dimension of illness is ignored. They end up seeing the importance of clinical ethics and arguing that it is indeed a part of medicine.

Medical students found the mock MCEC to be an engaging and educational exercise. This is evidenced by the passionate discussions and dialogue during the mock MCEC session. The evaluation that students complete at the end of the module are unanimously positive. They found it to be an amazing module that effectively taught them the relevance and importance of bioethics in patient care. One student noted:

> . . . interactive and informative. I loved the discussions, especially in the simulation of a real ethical board meeting. It definitely was a great learning experience and I realize how little I know about biomedical ethics. Thank you for a great course!

Another student commented, "the mock MCEC was an amazing experience" that helped him to "delve into the mindset of the members I was assigned to be. It was a one of a kind learning experience for sure."

The mock MCEC, held as a part of the PPS2 course, is a paradigm for teaching ethical decision making to medical students, placing them in positions in which they may find themselves a few years from becoming fully fledged medical doctors.

Conflicts of Interest

The authors wish to express that there were no conflicts of interest in writing this paper.

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CASE 1

Helping the Family of a Kidney Transplant Patient Accept a Do-Not-Resuscitate Order—Part 1

The Editorial Group of the John J. Lynch MD Center for Ethics

Complexity: 1 2 3 4

PRESENTATION

Mr Singh is a 72-year-old male, dying of multi-organ system failure and sepsis at a southern hospital. The patient was admitted to the floor over 8 weeks ago with pneumonia. He has been in the intensive care unit (ICU) for two weeks now, ventilated and on broad-spectrum antibiotics but continuing to decline.

Mr Singh received a kidney over 12 years ago at the same hospital; the chief of the transplant department, Dr Samuel Jones, performed the surgery. Dr Jones continues to serve as the patient's nephrologist all these years and has grown close to the patient and his family. Since the patient was admitted to the ICU, Dr Jones has recused himself from the patient's care, appreciating that he might be unable to remain objective about what is in the patient's best interest. The patient's consulting nephrologist is one of the hospital's senior attending physicians. In addition, one of the transplant fellows sees the patient daily.

At the continuing insistence of the family, Mr Singh's resuscitation directive has remained full code. Several days ago he went into kidney failure and has now lost function of the transplanted kidney. The remaining native kidney has failed also, and the patient has been placed on dialysis.

Late on a Friday afternoon, the ICU attending requests an ethics consult. The ICU attending informs the clinical ethicist that the full ICU team, as well as the consulting nephrologist, believe that the patient is dying, and that if the patient suffers a cardiac arrest, there should not be a resuscitation attempt. The ICU attending also informs the clinical ethicist that the team has tried to discuss shifting the patient's full code status to a do-not-resuscitate (DNR) order in the broader context of a full end-of-life discussion with the family, but the family has been strongly resistant to all such conversation. The patient's wife is the decision maker, and their two sons support her. The three are present daily at the patient's bedside.

On Friday evening, the ethics consultant comes to talk with the family. The wife has gone home for the evening, and only one of their sons remains. After introducing herself to one of the

sons, the ethics consultant says she is sorry to have learned that the physicians caring for Mr Singh believe he is dying, and that they are concerned about doing things to him that they believe will only cause harm without the possibility of any meaningful clinical benefit.

At this point, the son expresses that he does not believe that his father is dying, has not heard this from any of the physicians, and no longer is willing to talk to the ethics consultant. Instead, he politely but firmly demands that the patient's nephrologist and ICU attending come tomorrow morning with the clinical ethicist to speak with him, his brother, and his mother. The clinical ethicist responds that she will do her best to have the requested physicians available tomorrow morning at 10 a.m., to speak with the family together, but that she is not certain that she will be able to have this complement of physicians present to speak with the family on a Saturday morning on such short notice.

The clinical ethicist contacts the ICU attending to explain the son's response to the ethicist's attempt at an end-of-life conversation and to communicate the son's request for a meeting with the physicians the next morning. The ethicist leaves it to the ICU attending, who is fortunately already scheduled to come in the next day, to see whether she can reach the other requested physicians about their ability to join the family meeting the next morning.

ETHICAL ISSUES

The clinical ethicist believes that the ICU attending and others on the ICU team have attempted to have a full end-of-life discussion with the family. The ethicist believes it quite possible that the team has been explicit and has told the family that Mr Singh is dying, and the family has simply been emotionally unable to hear it. However, the clinical ethicist also considers that it may be just as likely that what the ICU attending believes has been an end-of-life discussion has not been as explicit as the attending believes.

The clinical ethicist has had many experiences in family meetings in which physicians who have been adamant that they plan to tell a family their precise expectations for the patient end up leaving without ever having said explicitly that the patient is dying.

Whether or not the ICU team had indeed communicated explicitly to the family that Mr Singh was dying, and the family simply could not process this information, resulting in a situation in which they might as well not have been told, a well-trained clinical ethicist knows by experience and close observation of hospitalized patients and physicians that there is a special trust that patients and families experience with their physicians. Whether that is because a patient is in a "must have trust" position, owing to the inherent power differential in the relationship, or if a patient and family have a special preference for their own physician, or for some other, even less tangible reason, the functional outcome is the same. Even in the busy world of today's high-tech ICUs, there is something unique about the relationship between physician and patient, and/or the patient's family, that is qualitatively different from any other relationship patients and/or family members will have with the many health professionals who work in an ICU.

In this case, the clinical ethicist does not take offense at the abrupt ending of her meeting with the patient's son. Depending on the situation, sometimes a skilled clinical ethicist will intentionally use the word "dying" to provoke a response from a family member who has shown particular difficulty in having a realistic conversation with members of the healthcare team. Indeed, this clinical ethicist intentionally used the word "dying" to learn for herself what the son's response would be. The provocation, albeit gentle and compassionate, wasn't intended to result in any particular outcome; one can never tell what outcome, precisely, will eventuate by the use of the word "dying." Further, the clinical ethicist will be one who, rather than being expected to be objective (an unrealistic expectation), instead has been well-trained and has acquired the skill of arriving at each case with a sense of neutrality in relation to its outcome. Rather, the anticipated result of the use of the word "dying" is that it ordinarily provides the clinical ethicist with important information about the family. Here, the response results in a demand for what is clearly a needed conversation with the patient's physicians.

RECOMMENDATION(S)

Set up a family meeting for the next morning at 10 a.m. with as many of the following parties as possible: the patient's wife and two sons, the patient's ICU attending, one or more of the ICU nurses, and the ICU social worker, all of whom know the family. In addition, the attending nephrologist and the nephrology fellow, and the clinical ethicist.

This case is continued in Case 2.

CASE 2

Helping the Family of a Kidney Transplant Patient Accept a Do-Not-Resuscitate Order—Part 2

The Editorial Group of the John J. Lynch MD Center for Ethics

Complexity: 1 2 3 4

PRESENTATION

The next morning, as the professional staff began to convene, not only are all the parties called for present, but there are, in addition, a significant number of ICU residents, interns, and fellows. To the surprise of many, the chief of the transplant department, Dr Jones, is also present.

The ICU attending starts the meeting, but the only person the family members want to speak with is Dr Jones. Before saying anything else, Dr Jones explains to the family that he has not been taking care of Mr Singh in the ICU because of his closeness with the patient and his family. He talks briefly about the warm relationship he, the patient, and the patient's family have had for over a decade. Dr Jones says the reason he has recused himself from Mr Singh's care and turned it over to Dr Wilson is that he, like the family, is terribly upset at the thought of Mr Singh dying.

The shock to the family from Dr Jones's use of the word "dying" is palpable. The wife and sons almost gasp for air. The son with whom the clinical ethicist spoke the night before speaks next. Talking directly to Dr Jones, he tells him in a rush of words that the first time he heard anyone say his father was dying was last night from the clinical ethicist. Moreover, that this was not something he took to be the case, nor believes it to be the case, now. At first, Dr Jones responds to the son by gently asking how he believes his father has been doing over the last eight weeks. The son responds that his father hasn't been doing very well, but that it doesn't necessarily mean he is dying. Dr Jones then asks the family if they remember how sick Mr Singh was when he finally received his kidney. After a long pause, the wife says, "Yes, I remember. He was close to death then." She goes on, crying, "But you saved him then, and he's been fine all these years. You have to do everything you can to save him now."

At this point, Dr Jones gets out of his chair, where he has been sitting directly across from Mrs Singh. With the full array of professionals on both sides of him and with no one else saying a word, he kneels in front of Mrs Singh and starts quietly talking to her about how they are not going to be able to save her husband this time. He talks to her about how sick he is, and that the antibiotics have not been working; how not only have both of

his kidneys given out, but his lungs and heart are failing. Mrs Singh begins to cry harder and raises her voice, saying, "You have to do everything to save him!" Dr Jones, holding Mrs Singh's hands, remaining on one knee and looking up at her, continues to explain that doctors are moral agents too; that they can't be compelled to do things they feel are wrong to do to patients just because the family, understandably, wants them done. Dr Jones talks for a very long time about why doctors have to be able to make their own moral decisions about when to try and bring a patient back and when not, depending on the condition of the patient, no matter how terrible the family's grief.

Finally, after about an hour on one knee, Dr Jones sits back down in his chair. He says how terribly sorry he is that he doesn't think Mr Singh will leave the hospital alive, and how important it is for Mr Singh's good care that the doctors not do things to Mr Singh that merely postpone his inevitable death. Mrs Singh whispers that she understands and shakily, with a son on each side of her, stands up, and the three of them go back to the patient's room.

Dr Jones then walks out, and the rest of the group take a deep breath and go back to their other responsibilities.

ETHICAL ISSUES

First, everyone at the family meeting has been party to one of the most accomplished physicians in the hospital humbling himself in the face of a grieving wife and sons. He demonstrates such loving care of the family; it is as if they are the only persons in the room. And from the moment the family sees Dr Jones, they are not interested in talking with anyone but him. They have come to trust him so much through the many years of Mr Singh's illness that he became the only one in the room who was going to be able to help them make sense of the present set of circumstances.

Dr Jones demonstrates for all the professionals in the room how to face the gravity of a patient's death with deep compassion for the family's grief while retaining a physician's integrity. Especially in today's busy ICUs, he demonstrates in an emotionally robust way what it takes to truly communicate with a grieving family at the end of a patient's life, while retaining the composure to discern what is and what is not in the patient's best interest. Even though he has recused himself because of his doubts about his ability to keep an appropriate distance in order to make unbiased medical decisions for the patient, in the end he shows everyone that he is able to do so. His heartfelt expressions of sadness at the prospect of Mr Singh's death are still delivered with the confidence to stand his moral ground.

RECOMMENDATION(S)

1. The attending physician should now write the do-not-resuscitate (DNR) order. The wife's admission that she understands and the lack of argument from the sons should be taken as agreement, even if tepid. The wife is the decision maker, and therefore it is not be appropriate to seek consent from Mr Singh's sons. In light of her grief, there is no need to seek anything more definitive than she gives. Her response to Dr Jones indicates that what she understands is that the physicians are not going to resuscitate her husband. It might not indicate that she *accepts* that he is going to die, but this is not required. All that is ethically required at this time is a lack of contest.

2. When the team considers it medically appropriate, other life-extending measures that are considered to no longer be providing clinical benefit should be limited, or capped, at a minimum, when reasonable standards of practice are reached or exceeded.

REASONING

This case provides at least three major areas for contemplation of moral medicine: the ethical aspects of the physician/patient relationship, a physician's integrity and moral agency, and what is required to consider an agreement valid when it concerns a DNR order.

During an invited address at the New York Academy of Medicine in 1952, Dr J.H. Means, in commenting on the recent flurry of conversation about the doctor-patient relationship, noted, "The most vivid thing I can remember about it in my early days, is that I cannot remember having heard much of anything about it."[1] If Dr Means' memory was correct and representative of medicine in general during that time, then attention to the doctor-patient relationship is a current phenomenon, possibly corresponding to the vast changes swept into modern medicine as a result of the social upheaval occurring in the United States during the 1960s. This was the time of the Vietnam War and presidential impeachment, and of attention to social justice issues across gender, age, and ethnicity, particularly that of the African-American community in the United States. It was a time

when authority of all kinds was being questioned and challenged, and to no greater effect than in Western medicine.

Although there existed a time during which families would not have even considered suggesting a course of action contrary to what a physician had decided, today, Mr Singh's wife and sons feel perfectly appropriate in requesting that every life-extending technology available be applied. It would have been astonishing, 50 years ago, for a patient's son to demand a next-day meeting with senior physicians, at a late hour on a Friday night, and to have such a request go unquestioned. That simple interchange between a family member and a hospital clinical ethicist speaks volumes to how much current medical practice bends to the will of patients and families.

That the meeting happens and includes the transplant surgeon, who performed the surgery over a dozen years before, is also impressive. His attendance at the meeting shows how much he cares about this patient and the patient's family. That he spends well over an hour on one knee speaking to Mr Singh's wife says how deeply affected this surgeon is—how passionate he is about trying to help her understand. His posture alone makes it evident to all present whom he considers to be the most important person in the room—the wife, not the surgeon.

Nonetheless, Dr Jones never wavers in his belief that the patient is dying, and that standing in the way of Mr Singh's inevitable death was wrong. Dr Jones tells Mrs Singh and her sons that performing a kidney transplant on Mr Singh all those years ago was an intervention that Dr Jones believed was plainly in the patient's best interest. He explains that now, however, resuscitation is not an intervention that is indicated, and therefore he will not do it.

Lastly, what circumstances are sufficient for a physician to write a DNR order unilaterally—over the objections of a patient's wife and sons? For most of historical medicine, physicians did everything they could to save and sustain life. There was no thought of not using anything at one's disposal, given that there was so little that could be done, for so long. With the widespread use of antibiotics in the 1940s, the first successful kidney transplant in 1954, and the advent of cardiac monitoring in the 1960s, suddenly there were ways to prevent death that previously had been unimaginable. The public, at least in affluent countries, became accustomed to people not dying.

The timeline of the development of these medical marvels crossed paths with a social movement that, at once, gave patients newfound control over their healthcare. Contemporaneously, there was an increasing concern about legal liability for physicians and hospitals. The reaction to these concerns has been the intensification of the documentation of informed consent over the years. Although volumes have been written about the topic of informed consent in medicine, there is little consensus about how much information is the right amount, or what kind of information is the right kind, or to what extent the person giving consent has to demonstrate understanding in order to be considered to have been sufficiently informed.

Our scenario presents us with an intensely grieving wife, exhausted from sitting at her husband's hospital bed for weeks, with two devoted sons who are trying to help and who are respectful of their mother's position as the medical decision maker. Must this wife co-sign the DNR? Must she give some sort of formalized, written consent? Or is her acceptance of the facts that Dr Jones fully provides, without an open and explicit contest, enough?

The answer to these questions depends on the answer to the following: "Enough for what?" This question, at the heart of informed consent problems regarding DNR, has a relatively simple answer, that is, "Enough for the physician(s) and hospital's attorneys to relax about whether or not they will be sued."

That being said, if this hospital's legal department is populated by attorneys who know that sound legal guidance to their physicians should be to simply broadcast through the hospital's physician population "Practice excellent, consultative medicine, and let the chips fall where they may. We will back you," the ethically best answer is likely to emerge. Moreover, such attorneys will know that, in this case, this wife's resigned, "I understand" is enough. Would it be enough for you and your hospital?[2-6]

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CASE 3

Sometimes It's Going to Be Zebras

The Editorial Group of the John J. Lynch MD Center for Ethics

Complexity: 1 2 3 4

PRESENTATION

When EV died, he was a 70-year-old Caucasian male who for some time had been seen by both his community cardiologist and a transplant cardiologist in an Advanced Heart Failure (AHF) group. Discussions regarding the possibility of transplant began when EV was referred to the AHF group 10 years prior, due to stage D, or "end stage," cardiac disease. But EV was ambivalent and returned to his community cardiologist. The AHF physician suspected sarcoidosis, but EV didn't pursue testing at that time. Perhaps if he had, the rare diagnosis of sarcoidosis might have been made in time to change the course of his disease. By the time an additional putative diagnosis of sarcoidosis was made, it was too late. Sarcoidosis is a disease in which granulomas, clumps of inflammatory cells, form in various organs.

EV was a big man, six feet, four inches tall, and 280 pounds. His blood type B was favorable for consideration of transplant. Not one to exercise, EV nevertheless had never had any serious illness. Fifteen years before his death, EV became acutely short of breath walking from his office to his car in the office parking lot. When it happened again walking up the stairs to his home office, he and his wife thought it best to go to their local urgent care center. When the senior urgent care physician had problems hearing EV's heart sounds clearly, he asked to do an electrocardiogram. Almost immediately, the technician returned from performing the test to talk to the physician privately. The physician went to check himself, and came back to EV's wife saying, "I believe your husband is in heart block. Shall I call the ambulance, or do you want to drive him to the hospital yourself?" To which the wife replied, "Please call an ambulance. I'm not risking him having something go terribly wrong when he's in the car." With that, an ambulance was called, the urgent care center doors were fully expanded, and EV was taken to his local hospital, which happened to be an ex-

cellent suburban heart hospital. Once admitted, a single-sided pacer was placed. Before placing the device—standard practice—a cardiac catheterization was performed. To the cardiologist's surprise, EV had perfectly clean arteries. EV went home three days later, returning to work the next week. There was no workup suspecting anything else wrong but congestive heart failure (CHF), perhaps because the cardiologist only thought of horses when he heard the sound of hooves.

The single-sided device had lasted about five years when, as is often the case, the other side of the patient's heart malfunctioned and a double-sided pacer with an implantable cardiac defibrillator (ICD) was placed. EV went home a week later, stayed home for an additional week, and again returned to work. This time, however, the patient was referred to the AHF group at his regional tertiary care hospital. Because there was no obvious etiology for the heart problem, the patient's AHF cardiologist wanted to better understand why the patient was having heart failure. He mentioned the possibility of sarcoidosis.

EV, however, didn't like the prospect of more tests, was put off by the size and bustle of the tertiary care facility, and chose not to have the testing done. Instead, he returned to the care of his suburban cardiologist, who answered the patient's and wife's questions about why the problem had started, with "Sometimes, we just don't know." EV, not being one to push his physicians, accepted that answer. This was, perhaps, a mistake.

Another 10 years passed, and EV was found to have atrial fibrillation. He was successfully cardioverted at his local hospital and returned home. This time, however, things did not progress well. In a matter of days, he was back in the hospital with a fluid overload of 40 pounds, and required increasing amounts of oxygen. Even as the excess fluid was reducing, EV's oxygen requirements continued to rise. At that point, a pulmonologist was consulted.

The pulmonologist arrived and—unable to make a confirmatory diagnosis, since EV was too ill for a lung biopsy—he put the patient on steroids, based on a putative diagnosis of sarcoidosis. Steroids, the standard treatment, helped within 24 hours, suggesting that the diagnosis was correct. By then, however, in conversation with a thoughtful and caring hospitalist, EV had agreed to a do-not-resuscitate (DNR)/do-not-intubate (DNI) order. Several days before that, in conversation with his community cardiologist, EV had decided against any AHF interventions, neither a transplant nor any ventricular assist device (VAD) as a bridge to transplant. With his oxygen requirement reduced to outpatient levels, he was transferred home by ambulance, into a hospital bed in his living room, with a home health aide. He went home on more medications, with a drug regimen of almost a dozen different pills per week. He hated taking all the different drugs, some morning, some evening.

He was not someone who wanted to have his life "medicalized," as the patient described what he saw as the future with a heart transplant. With a transplant, EV knew he would be on a strict immunosuppressant drug regimen forever.

EV worked diligently with this physical therapist. He was determined to gain enough strength to make the flight of stairs back into his own bedroom and his own study. He hadn't been able to take a real shower in weeks. Instead, EV was taken to hospice several weeks later.

As he was dying in hospice, he said to his wife, "Perhaps I should have gone back to the AHF group. They might have found the sarcoidosis sooner, and maybe all my heart problems could have turned out differently." His wife replied, "Perhaps I should have pushed you more." To which EV replied, "But part of why our marriage has been so good all these years is because we never pushed each other."

Less than 24 hours later, after having his implantable cardioverter defibrillator (ICD) turned off, EV died peacefully in his sleep. Throughout, his wife never did push him. He was not someone who wanted to have his life "medicalized," as the patient described what he saw as the future with a heart transplant. With a transplant, EV knew

he would be on a strict immunosuppressant drug regimen forever. Although he wanted to live, he just didn't want to live like *that*. Even though a transplant could have extended his life, it was a kind of intervention he just couldn't face. He knew that such life-extending technologies just weren't for him.

ETHICAL ISSUES

EV exemplifies the kind of patient whose decisions cannot be said to be uninformed, nor were his choices limited by the quality of accessible care. EV was intelligent, well cared for, and knowledgeable about his disease and his options for the condition he believed he had. While EV was capable of understanding and acting on any degree of medical complexity a well-explored diagnosis might present, he was consistently presented only with incomplete diagnostic information.

RECOMMENDATION

Use this patient's story as a teaching case. In young to middle-aged adults who present with unexplained cough, shortness of breath, or constitutional symptoms, sarcoidosis should be suspected, within the structure of an appropriate diagnostic work up. In a time of highly complex end-of-life technologies, advanced technologies for diagnosis should also be applied to ascertain etiology of disease. Sound treatment depends on accurate and full diagnosis.

REASONING

It is likely, given EV's preference for limited medical intervention, that this patient was not one for whom life-extending technologies such as heart transplant would have ever been the best choice. Perhaps, however, if suspicion of sarcoidosis had been stronger when the patient presented originally, or his care had been paused later on for diagnostic review,[1] the arc of his cardiac disease might have been altered. Robert Trowbridge, MD, proposed "12 Tips" for teaching the avoidance of diagnostic errors. Tip 2 promotes a time-out approach similar to what already has been incorporated into surgical practice.[2] This pause process would involve the diagnostic team reviewing the data with "fresh eyes," working not to reframe the data in the old diagnosis, but rather to rebuild the diagnosis from the ground up. With such a pause, EV's doctor might have thought to look for sarcoidosis, and, if found, the choices EV would have made may have been different, as his decisions would have been differently informed. Even if sarcoidosis was only a theoretical possibility, it was a possibility that was never open to this patient.

Today, although cardiac sarcoidosis is still considered a rare and underrecognized clinical condition, it is recommended that for making such a diagnosis there be "a high level of suspicion and low threshold for screening."[3] If this recommendation had been well known, EV's history and physical might have included consideration of sarcoidosis for two reasons. First, this patient had plausibly experienced an environmental exposure that placed him at risk for this rare condition. EV grew up in Charleston, West Virginia, when chemical plants were so plentiful that their emanating stench was, depending on the weather, quite intense. But by the time the putative diagnosis was made and the pulmonologist asked EV if he had ever had any unusual environmental exposures, his growing years were so far in the past that the patient didn't even think to provide this information. Second were the skin manifestations, unusual skin growths on his face. But these were never considered as evidence of anything related to CHF.

Without something outstanding to grab EV's community cardiologist's attention, coupled with the patient's reticence about additional interactions with the various medical teams, even a physician well aware of sarcoidosis could have made a critical error when a rare diagnosis was lurking in the background.[4] In EV's case, perhaps one of the diagnostic errors was an overlearning of the principle of Occam's (or Ockham's) razor.

William of Ockham was a 14th century Franciscan friar and a student of logic. He is credited with developing *lex persimoniae,* or the law of briefness, a principle that has come to be known as Occam's razor. Occam's razor is an explanation strategy: it calls for doing away with unnecessary elements when arriving at scientific explanations for natural phenomena. In medicine, Occam's razor is a powerfully embedded way of thinking about diagnoses; if fewer elements of a patient's symptomatology can be assembled into a reasonably plausible explanation for what is wrong, the recommendation is often to not make it more complex than it has to be. This kind of approach may not be reasonable for 21st century disease diagnostics, wherein the complexities are of crucial importance in arriving at the proper diagnosis, leading to a useful treatment plan.

As American journalist H.L. Mencken once observed, "Explanations exist; they have existed for all time; there is always a well-known solution to every human problem—neat, plausible,

and wrong."[5] As medicine has progressed over the last 100 years, the rate of increase of scientific explanations about the human body and how things can go wrong has mushroomed. Combining an appreciation of the complexities of human disease and the complexity of modern methods for figuring things out can easily overwhelm medical students and other physicians in training. It is not hard to understand the need for heuristics (learning guides).

Trowbridge explicitly describes heuristics and how they affect clinical reasoning, and identifies the "anchoring heuristic" as a confirmation bias in which a diagnosis made early can become "anchored" in a physician's evaluation of a particular symptom or sign.[1] As a result of this "anchoring," a patient's physician may discount other information or possibilities.

The problem of potential overuse of longstanding diagnostic heuristics in medicine, especially for one as well established as Occam's razor, is that they may be reinforced by folk-science aphorisms such as "think of horses, not zebras," attributed to Theodore Woodward, MD, University of Maryland School of Medicine. Woodward seemed to have taught his students in the 1940s something to the effect of, "When you hear hoof beats behind you, don't expect zebras."[6] Today, one not infrequently hears a physician tell a resident or fellow, or more infrequently a patient's family member, when there is no satisfactory diagnosis, that it's not good to look for zebras when it's probably horses. But, in Tip 10, Trowbridge calls for physicians to "Embrace Zebras." Trowbridge translates this strongly held medical truism as, "A variation on Occam's Razor, this guideline stresses that common disorders occur commonly and that one can waste a great deal of time and effort considering the rare diagnosis."[1] Unfortunately for complex patients, more than common causes for common symptoms can go unnoticed. Until embracing zebras becomes an aphorism universally taught to residents, it is hardly surprising that a diagnosis such as sarcoidosis could be missed in the tsunami of older patients with CHF physicians are seeing today.

If, however, someone had thought of zebras when an otherwise healthy, middle-aged man presented with unexplained shortness of breath and cardiac conduction abnormalities, especially when a close look at the patient revealed skin abnormalities and possible chronic childhood exposure to environmental toxins, EV might be alive today. Certainly, this case might well be used to teach two important lessons. First, even the most rational and well-informed patient who wants to live may not necessarily want to live a life tied to physicians, hospitals, and medical technology. Second, with all the wonders of modern medicine, it is perhaps time to look for zebras when thinking only of horses.

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