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Providers working in living donor transplant programs face not only clinical challenges, but ethical ones as well. Donors are placing themselves at significant risk of death or injury to help another person. How do you make sure that donors understand all the risks involved, are truly willing to be a donor, and are not making the decision to donate out of guilt, fear, family pressure, or coercion? Even without pressure from family or the potential recipient, sometimes the donors' desire to help patients can blind them from understanding real reasons they cannot or should not donate . . . . . 89

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## Panacea or peril? Do new treatments save lives or do they endanger them?

### *Living donor programs still risky*

**W**ith the U.S. donor organ allocation system in a continuing state of crisis, listing thousands more desperate patients than organs available for donation, more and more transplant programs are turning to living donor programs to rescue people almost certain to die on the waiting list.

Once only considered for kidney donation, healthy people now also are giving portions of their lungs, livers, pancreas, and intestines to friends and relatives in need of a transplant. But is it a promising new technology or a case of too much too soon?

### *Risks to donor not evaluated*

According to statistics kept by the Richmond, VA-based United Network for Organ Sharing, the organization that contracts with the U.S. Department of Health and Human Services to administer the organ transplant waiting list, living organ donation increased by 16% between 1999 and 2000, to 5,500 operations, the largest increase ever in a single year. Last year, in the state of New York, a third of all liver transplants came from live donors.

But, even though the operations provide lifesaving miracles for people who are at death's door and free up more cadaveric organs for people who do not have such an option, many experts are critical of the rapid expansion in the use of organ grafts from living donors. The risks to the donor, on whom an unnecessary, major surgical procedure is performed, are not being properly evaluated. And there is almost

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**Bioethicists turn critical spotlight on themselves**

✓ *Like it or not, the business of ethics is changing*

As the practice of bioethics expands beyond the traditional hospital setting, it is becoming even more important that bioethics professionals develop a process to critically examine their own practice in much the same way they critique the practices of others. Does accepting payment for bioethics consulting necessarily compromise the professional advice given? For whom should bioethicists offer consultation? Are there any inappropriate venues? And, in what ways do health care environments, personal achievement, and prestige affect the practice of bioethics? . . . . . 91

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**Certified palliative care physicians on the rise**

✓ *835 now are credentialed*

The American Board of Hospice and Palliative Medicine (ABHPM) granted certification to an additional 56 physicians as of July 1, bringing the total to 835 physicians certified worldwide in the specialty of hospice and palliative medicine. The medical specialty of palliative medicine is devoted to achieving the best possible quality of life for patients and their families faced with a life-threatening or terminal illness. Physicians who achieve certification from ABHPM are recognized as experts in the practice of palliative medicine . . . . . 96

**COMING IN FUTURE ISSUES**

- U.S. organ broker offers to coordinate international human cloning and gene transfer efforts
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- Regulating gene research: Should the medical community support more government regulation, or would more regulation restrict advances?

no regulation on which centers are qualified to perform these procedures, they warn.

An editorial by Cronin and colleagues from the University of Chicago<sup>1</sup> in the May 24 issue of the *New England Journal of Medicine* criticized the growth in the number of programs attempting adult-to-adult living liver transplant in particular.

“Since 1997, more than 30 U.S. transplantation programs have performed more than 400 of these procedures,” the authors wrote. “Although six of these programs have performed only one procedure each, one program has performed more than 100. Twenty-three centers are planning to start such programs. Liver transplantation in adults with the use of grafts from living donors may initially have been regarded as a technical extension of the procedure for transplanting liver grafts from living donors into children. However, we are unaware of any formal analyses of whether it is ethical to perform the operation, even if donors and recipients provide informed consent.”

**Risky procedures, little data**

Unlike living kidney donation, which has been performed in the United States since 1954, adult living liver donation is a much riskier procedure, and there are little published data on rates of complications, and mortality, among the donors, explains **Elizabeth Pomfret, MD**. Pomfret is a liver transplant surgeon and director of the live donor program at the Lahey Clinic in Burlington, MA.

The adult procedure is even significantly much riskier than adult-to-child living donation, which was pioneered in this country at the University of Chicago in the early 1990s and has since gained wide acceptance.

Because the liver has the ability to regenerate, the removal of the left lobe of the liver from an adult — a relatively small segment — can be transplanted into a child, giving the child a liver that is sufficient and will grow as the child grows. The adult operation requires a much more sizeable graft of liver tissue, the larger right lobe, from the donor, explains Pomfret.

“We have some experience looking at people who have given their left lateral segment, a much smaller piece of liver than we are talking about with adult live donor transplants where we are talking about typically somewhere between 50%-60% of the adult liver volume,” she explains. “It is really a significant operation, there is potential for death, potential for a bad outcome.”

The pediatric procedure was studied in a clinical trial at the University of Chicago, and the results were published before other institutions began performing the procedure. But now, Cronin and co-authors state, the adult operation is widely being performed without enough clinical data on which patients make good candidates and exactly what surgical techniques are best.

“Morbidity attributable to surgical resection in donors of grafts for adult recipients has been reported to be as high as 50%, with complications including wound infection, injury to the nerves of the brachial plexus, and portal-vein thrombosis,” the authors wrote. “The most serious potential consequence of a right lobectomy or an extended right hepatectomy is death due to an intraoperative complication or postoperative liver failure. Although a right lobectomy performed in a healthy donor should carry a low risk of death, the mortality rate has not been clearly established. On the basis of discussions at professional meetings, as compared with reports in the literature, we are concerned that some centers may not be reporting deaths in a timely manner.”

Due to the seriousness of the situation, the authors called for the Centers for Medicare and Medicaid Services (CMS), formerly the Health Care Financing Administration, and private insurers to collect data on complications associated with the surgeries and limit coverage of the procedures to only those performed at designated “centers of excellence.”

### ***National database needed***

While there is a need for more and better information about the procedure, Pomfret says she is wary of inviting government restriction of a life-saving treatment.

“Whenever you talk about regulation, it gets kind of dicey. I think that, there needs to be some sort of comprehensive database, a registry if you will, where anybody doing live donor liver transplant is submitting their patients and their results,” she says.

“This is more to allow those of us in the community doing this to be able to really quote numbers that are reasonable to people considering doing this. ‘The rate of complications are X,’ she says. “Out of however many procedures that have been done worldwide or in the United States, there have been this many donors who have died, this many donors have required a liver transplant themselves because of complications, there have

# CME

questions

5. A database that collects information about a specific surgical procedure: the technique, patient information, complications, and outcomes, is known as:
  - a. an archive.
  - b. a registry.
  - c. a collective.
  - d. a report.
6. To ensure that living liver and lung-lobe donors are psychologically sound, have not been coerced, and are physically able to donate, it is essential to:
  - a. set up a process that allows the candidate to be evaluated separately by a social worker, psychiatrist, and surgeon, none of whom are associated with the transplant patient.
  - b. provide enough time for all clinical and emotional issues to be examined thoroughly.
  - c. ensure that the donor understands all of the risks the surgery entails.
  - d. all of the above.
7. A collection of expert essays on the “business of bioethics” appeared in which publication?
  - a. *The New York Times*
  - b. *Journal of Clinical Ethics*
  - c. *The Hastings Center Report*
  - d. *The Journal of Pain and Symptom Management*
8. The potential benefits of discussing realistic prognosis predictions with terminally ill cancer patients that are mentioned in this issue include:
  - a. saving money.
  - b. allowing the patient to prepare his or her family members and make necessary legal arrangements for dependents.
  - c. discouraging them from making plans to leave the hospital.
  - d. none of the above

been this many major complications, this many minor complications.’ That sort of information needs to be available.” Pomfret says she also is concerned about the number of small transplant programs “dabbling” in this surgery.

The Lahey Clinic has had extensive experience with performing liver and kidney transplants and has performed around 40 living donor adult liver transplants, she notes.

“What is important is there has to be tremendous skill in the team doing liver transplantation and liver resectional surgery, because the live donor operation is very different than the transplant operation,” she emphasizes. “Our program is the largest in New England, and I think — at this point — the third largest in the United States, and there are only a handful of programs that would have that significant volume.”

Attending meetings of transplant professionals, she has heard reports of donors taken to surgery only to have the team discover a problem that makes the resection impossible, she says.

“We have never had that happen,” Pomfret states. “We have an extensive evaluation that has ruled those things out without ever going into the operating room. That is not the case with many other programs, where there are clearly reports of people going into the operating room, being well under way with the operation, and finding something that — as far as I am concerned — probably should have been able to be diagnosed preoperatively.”

### ***Failures not documented***

Equally disturbing, she says, is the fact that these failed attempts are likely not documented when these centers report their complication rates.

“I consider that to be a major complication, but it is one that sometimes isn’t put into the complication pool,” she says. “It’s like, ‘Oh yeah, there are those aborted hepatectomies.’”

The American Society of Transplant Surgeons established a registry for adult-to-adult living liver donation surgeries. But, according to Pomfret, the database does not contain enough information yet to be useful.

“Most of the data we have come from the transplant meetings that we all attend and that is

where you are hearing things like, ‘They’ve done this many operations, that there have been two people who have required liver transplants as a result of complications worldwide, three reported deaths in the donor population worldwide, rumors of more.’ But, I think that is a problem when you have just have these rumors to go on.”

### ***New lung procedure quietly gains ground***

An even newer transplant procedure involves two living donors donating portions of a lung to create a set of lungs for a patient whose own pair are failing.

Known as a living lobar transplant, there is even less information in the medical literature about who is performing these procedures, what the rates of complications are, and which patients should be candidates.

“No one knows the exact number or the success rates at other institutions because those numbers have not been published,” says **Soon Park, MD**, assistant professor of cardiovascular and thoracic surgery at the University of Minnesota in Minneapolis. “We have not published because our numbers are so small. We have performed three operations, and all of these patients

and donors are doing well. But our program is still in its infancy.”

The procedure, performed on patients whose lungs are failing and are not likely to live the two or three years it often takes to get a set of cadaveric lungs, involves taking a lower lobe from one lung of two separate donors.

“What the procedure is about is taking a lobe, which is half of a lung. Take one lobe from each of two donors and then in the recipient you take both lungs out and put two lobes. So, essentially they are getting one lung, comprised of two lobes, one on each side,” explains Park.

The surgery was pioneered by Vaughn Starnes, MD, and colleagues at the University of Southern California, and researchers there have published some information, he says.

Their data indicate that recipients of living lobar transplants do roughly as well as patients who receive bilateral cadaveric lung transplants, he says. “As far as the recipient is concerned, it gives them a survival benefit as well as enhanced quality of life.”

**“Clearly, there is a lot of debate about whether it is reasonable to take otherwise healthy people and expose them to significant risks of liver transplantation, for example, solely for the good of another.”**

For the donors, however, the risks are significant, he admits. The procedure involves major surgery and will take between 15% and 20% of their lung tissue, which does not regenerate the way that the liver does.

“The impact on lung function is fairly minimal, however,” Park says. “People can even live with one lung. In patients who have lung cancer, John Wayne is a good example, one lung is sometimes removed. It is a big operation, but once patients survive the surgery, they do reasonably well. We don’t ask that of donors, of course, we take much less from them.”

Most donors are able to return to leading normal lives after recovering from the surgery, he adds. And, his center has seen no complications among their donors.

But, a report last year by researchers at Barnes-Jewish Hospital in St. Louis detailed complications among 62 donors who had undergone the procedure there.<sup>2</sup>

In their report, 38 of the 62 had complications, including 12 major problems and 55 minor ones. The major complications included a hemorrhage that required transfusions and a nerve injury that partially paralyzed the donor’s diaphragm. Minor complications included pneumonia, temporary problems with heart rhythm, and infections of the pericardium.

### ***Is it ethical?***

The problem for many in the transplant community is that complications in living donors are health problems *caused* by physicians in previously healthy people — the opposite of the mandate to “first, do no harm.”

But, for physicians in the transplant community faced with patients with little hope and donors asking to take the risk to save a loved one, going ahead with these procedures offers a chance they feel compelled to pursue, both for the individual patients and for the thousands more who must wait for a cadaveric organ.

“Clearly, there is a lot of debate about whether it is reasonable to take otherwise healthy people and expose them to significant risks, of liver transplantation, for example, solely for the good of another,” says Pomfret.

“It is the heart of a lot of ethical debates. But, I think that most people agree, at this point, who are doing this, that, if the donation is done in such a way that there is a genetic or significant emotional relationship between donor and recipient, then

## **SOURCES**

- **Soon Park**, MD, University of Minnesota, Department of Surgery, MMC207, 420 Delaware St. S.E., Minneapolis, MN 55455.
- **Elizabeth Pomfret**, MD, Lahey Clinic, 41 Mall Road, Burlington, MA 01805.

there is a rationale to allowing that person to take that risk.”

Both Park and Pomfret say they recommend limiting these procedures to patients who really have no other alternative — who most likely face death if they wait for cadaveric organs.

And, both say it is essential that centers offering these procedures devote significant resources to ensuring that the donors are not coerced into offering the donation and that they fully understand the risks. **(See related story, below.)**

Given that 10%-20% of patients seeking lung transplants die on the waiting list and that lungs can be harvested from only 10%-15% of cadaveric organ donors, Park feels that the procedures have a place.

“I would not say that this is something that should be recommended as being an alternative to seeking cadaveric lung donation,” Park says. “But, given that the availability of organs is so low, and the death rate on the waiting list is so high, I think it should be done in limited situations, and, possibly, expanded as we learn more.”

### ***References***

1. Cronin DC II, Millis JM, Spiegler M. Transplantation of liver grafts from living donors into adults — too much, too soon. *N Engl J Med* 2001; 344(21):1,633-1,637.
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## **Living donors require adequate protection**

### ***Make sure risks are understood***

**P**roviders working in living donor transplant programs face not only clinical challenges, but ethical ones as well.

Donors are placing themselves at significant risk of death or injury to help another person.

How do you make sure that the donors understand all the risks involved, are truly willing to be a donor, and are making the decision to donate out of guilt, fear, family pressure, or coercion?

“We have learned along the way that, really, some donors are forced or coerced into this,” says **Elizabeth Pomfret**, MD, director of the living donor program at the Lahey Clinic in Burlington, MA. “Maybe they are the member of the family who doesn’t have a job, or they are the one the family decided should be the one who does it, and there are these outside pressures put on these people.”

### ***Develop a foolproof procedure***

Even without pressure from family or the potential recipient, sometimes the donor’s desire to help the patient can blind that person from understanding real reasons they cannot or should not donate.

That’s why it’s essential that living donor programs have a foolproof procedure for evaluating potential donors that is completely separate from the process of evaluating the patient’s qualifications for undergoing the procedure, advises Pomfret.

Not all people who want to be a donor will qualify.

“One of the more important criteria that has to be met is the issue of anatomy,” Pomfret explains.

“The liver is much less finicky from a genetic standpoint than the kidney; you need to match genetics there much more closely than you would for liver transplantation. But with liver transplantation, it comes down to an issue of size,” she points out. “We know we need to leave the donor with at least 30% of what they started with in order to be safe. We know we need to give the recipient about 1% of liver volume to body weight. For instance, you have a 70-kg person; we need approximately 700 g of liver tissue. So, the size, blood vessel anatomy, the anatomic considerations become more of an issue in live donor organ transplantation.”

At Lahey, a surgeon, psychiatrist, and social worker give the prospective donor a thorough clinical and psychological work-up to determine if there are any medical or emotional reasons why the procedure shouldn’t be performed.

“The medical evaluation of the donor is conducted by a physician who has never met the recipient, so that has no bearing on their conclusions,” she says. “The psychiatrists are completely different than the ones evaluating the

recipient. The steps are set up along the way so that if there is coercion or family pressure, those things will be culled out during the course of the evaluation.”

If the counselors determine that the person is not truly prepared to be a donor, they usually “construct” a vague medical reason why the person cannot participate, Pomfret says. “You have to have a way in which the donor can bow out without becoming the bad guy in the family. The family is usually told there is some anatomic abnormality which is not harmful to the donor’s health, but makes it impossible to divide the liver in two.”

Prospective lung lobe donors at the University of Minnesota also are evaluated by a separate team of physicians, psychiatrists, and social workers, says **Soon Park**, MD, assistant professor of cardiovascular and thoracic surgery.

If a potential donor is ruled out for any reason, medical or psychological, they are only told that they have not been cleared as a candidate, he says. “They know up front that the answer is just yes, you can be a donor; or no, we cannot accept you.”

Sometimes, even if a potential donor meets both clinical and psychological criteria, the surgeons themselves may have qualms for other reasons.

### ***Altruism still questionable***

Both Park and Pomfret say they would have problems with, and probably would not accept, a donor who did not have either a close familial or emotional relationship with the recipient.

“I think many people are still in debate as to whether or not Good Samaritan donations should be done, people donating who have absolutely no relationship [to the recipient] whatsoever, who are just looking to do this for altruistic reasons, there is a lot of debate over whether that is reasonable to pursue in this situation,” she says. “And, to this point, we do not do Samaritan donations, but there are groups in the United States that do.”

Nondirected donations, or list-paired donations, might be acceptable for kidney donors, where there is enough past data showing that donors go on to have normal lives and their future is not severely affected by the donation, she adds. “We certainly do not have that level of experience in either lung or liver donation.”

Park admits he initially had reservations about performing a living lobar transplant with a donor

## RESOURCE

- The American Society of Transplant Surgeons has initiated a registry of living liver donor procedures and developed a position paper on adult living liver transplants. For information, visit the ASTS site on the web: [www.astst.org](http://www.astst.org).

who was not related to the patient, but was a friend.

“I really could not believe that someone would go through such a procedure like this. I thought that there must be something going on somewhere, something was wrong,” he says.

But, the woman made it through the screening process and talked with Park himself and convinced him that the procedure should be done.

“I am convinced that some people out there just have really good hearts,” he says.

Even if the potential donor is related, there are some cases that Pomfret feels surgeons might still impose their own ethical judgements.

“From my perspective, I am always concerned when we are talking about a donor who has young children,” she says. “Certainly, say a scenario in which the husband needs a liver transplant, the wife wants to be the donor, and they have children under the age of 10. You have to really think about, ‘Is that a reasonable thing for her to do?’ By and large, that sort of scenario is not something we would do at this point.”

### Further Reading

- Authors for the Live Organ Donor Consensus Group. Consensus statement on the live organ donor. *JAMA* 2000; 284:2,919-2,926. ■

## Bioethicists turn critical spotlight on themselves

*Like it or not, the business of ethics is changing*

As the practice of bioethics expands beyond the traditional hospital setting, it is becoming even more important that bioethics professionals develop a process to critically examine their own practice in much the same way they critique the practices of others.

Does accepting payment for bioethics consulting necessarily compromise the professional advice given? For whom should bioethicists offer consultation? Are there any inappropriate venues? And in what ways do health care environments, personal achievement, and prestige affect the practice of bioethics?

These are some of the many questions that experts in the field are beginning to ask of themselves and others as both health care and medical ethics rapidly expand beyond traditional horizons.

“Bioethicists, usually philosophers and humanists, were traditionally asked to go into the hospitals and take a look at difficult clinical cases. And, the model of clinical ethics consultation is based on that paradigm,” says **Laurie Zoloth**, professor of social ethics and Jewish philosophy at San Francisco State University in California.

“While there was interest, at that time, in whether you could be paid directly or not — it never reached the pitch that it has recently. Now, bioethicists are being asked by biotech companies and pharmaceutical companies to do the same thing, to come into an unfamiliar venue where there are significant ethical issues and bioethical issues, and take a look at these.”

### *Is it appropriate?*

Zoloth was one of several academic bioethicists contributing to a series of essays examining the “business of bioethics” in a recent issue of *The Hastings Center Report*.<sup>1</sup>

She finds it interesting that, for years, bioethics professionals have been urging pharmaceutical corporations and third-party payers to critically examine ethical issues, but, now that they are asking for help, there is a great deal of debate over the appropriate way to do this.

“Now, the private sector takes us seriously and says, ‘OK, come take a look, tell us what you think,’” she says. “Once we are asked to go, the question becomes, ‘Do you do it for free? Do you take money for it?’ Suddenly, you are in a different world.”

Payment isn’t the only issue, she adds. Many bioethicists are concerned over requests that they sign privacy and confidentiality agreements.

“It is not that we are unfamiliar with privacy and confidentiality, that is supposed to be our business,” she continues. “Suddenly, we are in a world where the first thing one does is sign a nondisclosure form, which feels different. Actually, it is not that different from not disclosing your patients’

information, or not disclosing research results prematurely. But, it does take people aback.”

### **Payment and the power to corrupt**

Some ethicists have argued against accepting payment for private bioethics consultations. Money, they argue, would inherently compromise the process — in ways subtle and not-so-subtle, the consultant would be less likely to criticize the “employer.” Zoloth doesn’t agree.

“If it should all be pro bono, then we shouldn’t take money from foundations or universities or anybody,” she says. “Many people work as clinical ethicists in hospitals. Should you say, ‘Pay me a *de minimis* amount, half of what I make at a hospital, or the same rate as what I make at a hospital?’ Why is that different? A large hospital asks for my opinion and pays a certain rate, and a pharmaceutical company asks for my opinion and does as well. All money comes from somewhere.”

The debate about payment is largely confined to academic circles, where bioethicists can “afford” to discuss pro bono work because they have tenured faculty positions with major universities. That discussion fails to consider the health care professionals who may have both a background in clinical and ethical study and now make their living in the private sector, she admits.

**Jon R. Hendrix**, EdD, retired professor of biology and science education at Ball State University in Indianapolis, founded the school’s Human Genetics and Bioethics Education Laboratory, and served for nine years as a member of a hospital ethics committee. He now runs a private bioethics consulting business that works with two community hospital systems.

His consulting is both corporate and clinical — helping the systems develop ethical business policies and helping the standing ethics committees resolve difficult clinical problems.

“It’s a constant battle,” he says of the need for consultants to examine the context of working relationships. “It must be a constant battle; we are human beings and are subject to all of the frailties thereof. The interest of people who listen to you in a group, the feedback you get, all of these are subtle motivators.”

Zoloth agrees that money is not the only element with the power to compromise.

“The questions I am interested in have less to do with money,” she says. “I think one can be tempted by money, but I think it is pretty easy, especially if you are an academic and you have tenure, to say, ‘Oh, well, I’ll do it for very little money, or I’ll do it for no money,’ that we should all do it pro bono. I don’t think even that solves the problem. I have seen principals get up in meetings and talk about all their work and get all of the secondary benefits, for their careers and their publications, because they have done the work. Even if they don’t get a dime, they have the

access to power and the access to secret knowledge. For me, I wanted to push us to look not only at the issue of money, but to look at the issue of how we handle, and are shaped by, the kinds of consultations that we do.”

It’s a complicated area, notes Hendrix. In his arrangements with the hospital systems, he charges a flat rate that is paid out of money from a hospital foundation, he notes. Therefore, he feels able to agree or disagree or challenge decisions the hospitals want to make.

However, he has seen how other arrangements, both financial and organizational, would make it difficult to remain objective.

“There are some hospitals that have chosen, after the Joint Commission came up with the requirement that you have a formalized method of resolving ethical issues, some have chosen to just pick a consultant [to perform this function],” he says. “And, some have just picked a consultant they know will agree with them, as long as that consultant is being paid.”

### **More than decision making**

Frequently, the consultants end up feeling that it is their job to simply come in and render the “ethical” decision, Hendrix says.

“I maintain that a good bioethicist in a group dynamic learns to ask questions, rather than immediately give solutions, learn to be a real questioner and draw forth solutions from the group, rather than impose solutions yourself,” he says. “You are there really as a facilitator helping them meet this need. There are bioethicists

**“It is always important to work with ethics committees . . . and colleagues so that you aren’t the lone gun being hired like in the Wild West to come in and fix something. You are part of a moral community and you are accountable to somebody.”**

who have literally come in and said, 'This is what I recommend,' and that scares the living daylights out of me because it is such a values imposition. It never allows for growth in the community for which you are working."

### ***Maintaining the 'humility' of bioethics***

The key to preserving one's own equilibrium is to self-impose a system of checks and balances, Zoloth believes.

"Some of the ideas that I had, are that you don't do it alone," she says. "Where you have a large group of people, and you can ask and answer questions. It is always important to work with ethics committees, and to work with colleagues, so that you aren't the lone gun being hired like in the Wild West to come in and fix something. You are part of a moral community and you are accountable to somebody. You should always have the sense that it is not you vs. the company. It is you, and the company, and the society, and it is the society to which you are responsible."

Disclosure to others of the work you are doing is also important, she says.

"It is extremely important to disclose who you consult for and how you've done the consultations," she says. "You shouldn't be ashamed of any work you do — they ought not to be ashamed of consulting a bioethicist and you ought not to be ashamed of having spoken to a company. And, I think future clients have a right to know who you've worked for, if you are talking about a particular drug or technology, if you have previous experience with that."

### ***Identify the parameters***

And, in going into consultations, it is important to very clearly spell out what is expected by both parties at the outset, says Hendrix.

"You need to very carefully spell out the parameters of that consultation so that you are not roped into doing things that you are not, first of all, adequately prepared to deal with, and secondly, qualified to deal with," he says. "There are some things I may feel qualified to do, but feel that I have not been given enough time to be adequately prepared to deal with. I think that when you are doing consulting, you need to know some of the parameters, and whether the time constraints allow you to do that. Do some *real* thinking about that before you go into a group."

## **SOURCES**

- **Jon R. Hendrix**, 107 Glasgow Drive, Edinburgh, IN 46124.
- **Laurie Zoloth**, San Francisco State University, Department of Jewish Studies, 1600 Holloway Ave., San Francisco, CA 94132.

It is high time that bioethicists examined their own practice in much the same way they examine the practices of companies, health systems, and hospitals, she says. "I do think it is important that we turn our attention, as a field, to the work that we do. We often critique others, and it is important to turn that focus on ourselves as well. We have spoken a lot about conflicts of interest with researchers, and while I think it is legitimate for us to raise this issue, we also ought to raise the issue of conflict of interest with one another."

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### ***Further Reading***

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## **Note to physicians: Talk to patients about end-of-life**

### ***Innovative program offers legal advice***

**I**n her practice as a gynecologic oncologist, **Kerry Rodabaugh**, MD, assistant professor of medicine at the University of Missouri Health Sciences Center in Columbia, often is faced with a situation her training didn't prepare her for.

For many of her terminally ill cancer patients, their concern is not what will happen to them as they face their disease, but what will happen to their children after they are gone.

"I take care of a lot of patients who happen to be single parents, and I didn't know how to help them with their children," she says. "And, that was one of the most distressing things for them as they went through their disease process, was who would take care of their children?"

Last year, Rodabaugh conducted a small study to find out how well the custody arrangements her patients had made held up after their deaths.<sup>1</sup>

What she found was even more distressing.

In 40% of the cases, custody of the children was granted to individuals to whom the deceased parents were explicitly opposed to being made responsible for the children, she says.

"We identified several children — though our study was very, very small — who did not want to go with the person to whom custody was assigned," says Rodabaugh. "The situation even raised a suicidal crisis in one child who was sent to live with someone she did not know."

Half of the children also were unaware at the time of their mothers' deaths of the custody plans that had been made for them, she adds. "That was one of the problems that we identified. Sometimes, parents will make plans for their children but not necessarily share it with the children. I don't want to be paternalistic, but I don't really believe that's the best way."

### ***Patients get legal advise***

In many cases, the problem was that the women simply lacked appropriate legal advice, and that is something the hospital is trying to remedy. Since the study, Rodabaugh and hospital social workers have begun a pilot program in cooperation with the University of Missouri Law School to help terminally ill mothers get legal advice on custody planning.

"In some of the cases, they had made custody arrangements, but when they were challenged in court, they simply didn't hold up," Rodabaugh says. "Some of the children went through custody battles between fathers and stepfathers, which is certainly not good for the child, particularly so soon after the death of their mother."

In addition, Rodabaugh feels, it's important to raise the issue of custody planning earlier in a parent's illness, so that they are not faced with

this problem right at the time they are trying to deal with their own death.

"Some of it is that this is one of the last things that patients will address because when people start working on a custody plan, my sense is, they feel they have given up," she says. "Women do not want to give up on their own diseases because they feel like they have failed their children if they give up."

Rodabaugh recommends trying to raise the issue with parents earlier in the disease process, perhaps addressing it as a routine part of planning "just in case" something were to happen to the patient, she says.

The goal of her study, she adds, was to raise awareness in the clinical community that custody issues need to be addressed.

"It is something that people do not think of first thing; they are more interested in what the options are for treatment of the disease, whether you have pain adequately controlled —

those kinds of things," she explains. "But I am trying to get this a little more into the spotlight so that people address this issue also. I really think we can improve quality of families' lives if we can settle these issues earlier on in the disease process."

### ***Honest communication may be a problem***

Before such planning can be addressed, however, the patient must have a realistic picture of what his or her disease stage actually is. This may be a problem, as a recent survey of physicians with patients at five hospices in the Chicago area indicated that physicians may frequently give patients misleading information about their prognoses.

In a written survey of the physicians of 326 cancer patients and recently published in the *Annals of Internal Medicine*,<sup>2</sup> the physicians indicated that they would either provide no survival estimate or a deliberately incorrect survival estimate 77% of the time.

When asked whether they would provide an estimate of survival to patients who request it, the physicians responded that they would provide a frank estimate only 37% of the time; they would refuse to provide an estimate 22.7% of the time; and they would provide an estimate that was either overly optimistic or pessimistic 40% of the

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## SOURCES

- Elizabeth Lamont, MC 2007, 5841 S. Maryland Ave., Chicago, IL 60637.
- Kerry J. Rodabaugh, 704 Ellis Fischel Cancer Center, Columbia, MO 65211.

time. Of that 40%, most of the estimates would be “optimistically discrepant,” meaning that physicians would tell the patient an estimate longer than what they themselves believed to be true.

“Everyone wants the best for their patients and hopes that their patients can live as long as they’d like to,” notes **Elizabeth Lamont**, MD, assistant professor of medicine at the University of Chicago Medical Center, and co-author of the article. “But in our effort to make them feel hopeful about that, we may rob them of the opportunity to get what they need to get done before they die, whether that is getting a custody arrangement in place, or having children who live out of state fly in to say goodbye. You just worry about lost opportunities.”

In an attempt to give the patients hope, the overly optimistic physicians may in fact be doing their patients a real disservice.

Prior studies have shown that many physicians’ estimates of patient survival times are overly optimistic anyway, without meaning to be Lamont says.

“The problem is that there is a baseline overestimate that doctors aren’t aware of, then you add on to it, the overestimate that they are aware of,” she notes. “The patient ends up being twice removed from information about their survival because there is the subconscious error and conscious error.”

In the case of physicians who do not want to give estimates at all, a key problem may be that physicians themselves do not feel able to accurately predict a patient’s survival.

“One thing we found was that physicians who were very underconfident about the predictions they had made, they were more likely to say they would say nothing,” she says.

One solution, Lamont believes, is to shift the focus from prolonging life to ensuring the quality of the patient’s life, which means helping them plan to have a “good death,” she believes.

Although some physicians do not feel comfortable with survival estimates, she feels physicians should at least talk to the patient about survival rates among people with the same illness and similar characteristics.

“You may want to teach them about survival statistics. One thing to do would be to say, ‘It is very hard to predict for the individual, but we know that other patients who have the same disease that you have, that has the same extent, have a median survival of X number of months, and you’ve had this for six months, that means lots of people like you will have died in the next two months,’” she says.

Even though it may feel that the physician is “discouraging” the patient, part of the physician’s responsibility to see that he or she is aware of what their true condition is and can make arrangements that they want to, and expect to be able to make.

“It’s not really better to tell them they have

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### Editorial Questions

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three months, when it may be more like three weeks," she says. "I have talked to families after patients die and they would say, 'Gosh, you know, we just didn't see it coming,' and I think, how could it be that you didn't see it coming? But when you don't have these kinds of frank discussions. You can see how it might happen."

## References

1. Willis L, Peck M, Sims S, et al. Custody planning. A retrospective review of oncology patients who were single parents. *J Pain Sympt Manag* 2001; 21:380-384.
2. Lamont EB, Christakis NA. Prognostic disclosure to patients with cancer near the end of life. *Ann Intern Med* 2001; 134:1,096-1,105. ■

# Certified palliative care physicians on the rise

*835 now are credentialed*

The American Board of Hospice and Palliative Medicine (ABHPM) granted certification to an additional 56 physicians as of July 1, bringing the total to 835 physicians certified worldwide in the specialty of hospice and palliative medicine.

The medical specialty of palliative medicine is devoted to achieving the best possible quality of life for patients and their families faced with a life-threatening or terminal illness. Physicians who achieve certification from ABHPM are recognized as experts in the practice of palliative medicine.

"The art and science of care for patients who are not likely to be cured has always been an important part of the physician's role," says **Ronald Schonwetter**, MD, chairman of the ABHPM.

"Unfortunately, for the last generation of physicians, training in palliative care was not considered important. Physicians had to keep up with all of the technological advances in curative medicine. But all patients die eventually. And unless the physician is skilled in providing pain control, symptom relief, and working with a palliative care or hospice team, patients generally will not have the opportunities for comfort, dignity, and closure that they deserve. ABHPM diplomates are the physicians helping medicine realize the importance of high-quality end-of-life care," he says.

Eligibility requirements for certification from

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ABHPM are significant. Applicants for certification must have received prior major specialty certification, have practiced at least two years following residency, have worked as a member of an interdisciplinary team for at least two years, and have directly participated in the active care of at least 50 terminally ill patients in the preceding three years. Applicants who meet those requirements are then permitted to sit for the annual certifying examination, which covers pain in cancer and noncancer patients, management of nonpain symptoms, hospice and palliative approach to care, ethical and legal decision making at the end of life, death and dying, and communication and team work.

ABHPM will again offer the certifying examination on Oct. 13. Applications to sit for the examination must be received by Aug. 31, 2001.

*[Editor's note: A handbook for examination applicants as well as other information on the American Board of Hospice and Palliative Medicine may be obtained from the web site at [www.ABHPM.org](http://www.ABHPM.org) or by calling (301) 439-8001.]* ■