Changing Our Priorities in Organ Distribution

By Maryam Valapour, MD

Organ transplantation has become an important life-saving approach for the treatment of end-stage diseases. The demand for transplantation has been rising in the United States with an increase in the number of patients listed every year. The disparity between demand and supply has meant long waiting times and increasing death rates among patients on the waiting list.

The United Network of Organ Sharing (UNOS), administers the nation's only Organ Procurement and Transplantation Network (OPTN). It has the mandated mission of facilitating organ transplantation and developing national organ transplantation policy.

Recently the Thoracic Committee of UNOS was charged with the task of recommending a new allocation system with the goal of a more equitable distribution of lungs. In contrast to other solid organ transplants that are preferentially allocated to the most severely ill patients, the current OPTN/UNOS policy provides for the allocation of lungs based on patients'
time accrued on the lung waitlist. In other words, this is a “first come first serve” model. The mandate to reevaluate the lung allocation model largely came about due to the high mortality rate of patients on the waitlist.

In March 2003, the Lung Allocation Subcommittee presented its proposed new model to the lung transplant community for consideration and comment. The Subcommittee took the unique approach of considering who would receive the most benefit from the transplant as well as addressing the issue of reducing waitlist mortality. The new system proposed is a risk-stratified allocation algorithm. At the time an organ becomes available, the patient’s characteristics are used to calculate his expected probability of survival if he remains on the lung waitlist for another year. Then, his characteristics are used to estimate his expected probability of survival the first year after the lung transplant. The patient receives an allocation score based on the difference in these two numbers. Donor lungs will therefore be offered to the patient with the highest score.

**Is the new system any better than the old?**

In cases such as lung transplantation, where severe scarcity results in individuals dying, I argue that it is the moral responsibility of the medical community to distribute these scarce resources in a fair or just manner. What becomes problematic is defining what is fair in this context.

Intuitively, allowing the “good fortune” of being ahead in line for an organ to influence one’s opportunity to receive a transplant seems arbitrary. I use the words “good fortune” because the timing of when a patient is placed on the lung transplant list is influenced by factors such as when she was diagnosed, her physician’s knowledge of the disease and transplant allocation scheme, and where she lives. The differences in waiting time for transplantation can vary by years based on defined geographic regions alone.

The new system won’t allow for a patient to receive a transplant ahead of another who may soon die without a transplant. This new allocation system follows the “rule of rescue,” which is society’s theoretical willingness to expend medical resources to save the life of a sicker patient over one who is less severely ill despite stated decreased utility in a dying patient. This is important to bear in mind, as it is society from which donated organs come.

However, when resources are severely limited, does justice require that utility be considered? The emphasis on giving organs to the most urgently ill arises from the maxim that, all else equal, we ought to give the organs to those who will most immanently die without them. Should this obligation alone alter allocation priorities? This question deserves consideration because despite efforts to increase the donor supply, the shortage of cadaveric transplant organs continues to increase. And because it is a well documented fact that the medical condition of the organ recipient influences the degree of success of the transplant, the sicker the organ recipient is, the shorter the survival of the patient as well as their transplanted organ.

A system that targets reducing waitlist mortality only, as in a case of lung transplantation, will likely result in a net number of years of life lost because sicker recipients will not live as long as healthier recipients. This is significant in the case of lung transplantation where 5-year mortality rates are already as high as 50% under the current model where the very sick patients are not transplanted.

By ranking the candidates according to mortality criteria, the UNOS Lung Allocation Subcommittee is attempting to balance efficacy and urgency. However, the model does not truly give efficacy equal weight as it only looks at one year mortality post transplantation. This is problematic since there is variation in transplant survival based on underlying disease. For example an emphysema patient has different outcomes from a cystic fibrosis patient every year after a transplant. The expected post transplant mortality will significantly vary if you consider one versus five-year survival after transplant. If the goals of utility and reducing mortality are to be given equal consideration, the net number of years gained per organ ought to be considered rather than one-year post transplant mortality data.
Maryam Valapour received her Doctorate of Medicine from the Medical University of South Carolina and completed her residency in Internal Medicine at Thomas Jefferson University. She subsequently completed fellowships in Pulmonary and Critical Care Medicine as well as Bioethics and Health Policy at Johns Hopkins University. Dr. Valapour’s research interests include distributive justice as it relates to allocation of healthcare resources and transplant ethics. In particular, she has focused on the fair distribution of organs. Her research focuses on policies that govern the national distribution of lungs in patients with end stage lung diseases. Her latest project examines the policies of transplant centers to allocate one versus two lungs in patients with chronic obstructive lung diseases and whether that choice results in a mortality difference. She is now working on the moral analysis and ethical framework of defining fair and efficient organ allocation in cadaveric and living organ transplantation.

**Selected Publications**

**ARTICLES**


**Center News**

**FACULTY**

Carl Elliott, MD, PhD, will spend the 2003-04 academic year as a Visiting Associate Professor at the Institute for Advanced Study in Princeton, NJ. While at the Institute, Professor Elliott will be working on a book about the bioethics advice industry and running a bi-weekly seminar on bioethics.

Jeffrey Kahn, PhD, has contributed to a special report by the Consortium on Pharmacogenetics titled, *Pharmacogenetics: Ethical and Regulatory Issues in Research and Clinical Practice*. The report provides a systematic prospective analysis of the potentially profound effects pharmacogenetics may have upon both drug development and on clinical medicine. For a copy of the report, visit [www.bioethics.umn.edu/News/pharm_report.pdf](http://www.bioethics.umn.edu/News/pharm_report.pdf).

**VISITING FACULTY**

Raymond de Vries, PhD, has been invited as a visiting member for the 2003-04 academic year at the School of Social Science at the Institute for Advanced Study in Princeton, NJ. While in residence, Professor de Vries plans to begin work on a social history of bioethics, examining the conditions that prompted and shaped the professional project of bioethics. He will also continue his research, in collaboration with the Minnesota Center for Healthcare Ethics, on the ethical and policy issues surrounding the use of deep brain stimulation for treatment of Parkinson’s disease.
The vast majority of living donors are so-called related donors — that is, they have a blood, family, or emotional relationship to the organ recipient. This relationship creates both the impetus to donate and the crux of the ethical worries around the donation, since related donors may be willing or feel compelled to overlook the risks of organ donation when their loved one stands to receive so great a benefit.

The problem is that while the medical benefit to the recipient is great, all the risk of the donation falls to the donor. So we must ask whether the benefit to the donor of seeing a loved one’s life saved or health improved, along with the benefit of doing a remarkably good deed, is sufficient to balance the risk they are asked to undergo. The answer may well depend on the level of risk involved, which is substantially greater for donation of a part of the liver, lung or other organs than for donating a kidney.

Once an acceptable risk-benefit balance is established for particular living donations, the primary ethical question is whether the donor is making a voluntary decision. We can all imagine the pressure family members might feel to come to the aid of a loved one. And even when there is little implicit or explicit pressure, potential donors may be blinded by the hoped-for benefit of their donation, and literally ignore the risk to themselves.

Sometimes we call people heroes when they expose themselves to risk in order to save others, and organ donation can certainly be heroic. But there can be a fine line between heroism and foolhardiness, and the medical profession needs to be sure it can distinguish the two. So how far should we go with living organ donation? It is remarkable that medicine has the means to save more lives through transplant techniques that allow living people to give up part of their life-sustaining organs for others. But no matter how impressive the successes of living organ donation, we must redouble efforts and commitment to put safety first.

The transplant community should move down that path by working collectively to learn whatever there is to know when donors die, and by making clear that whatever benefits living organ donation has to offer, we should never expect potential donors to be dying to donate.

A version of this article appeared in Dr. Kahn’s column, “Ethics Matters” which appeared on CNN.com

Bioethics Institute For Life Science Faculty
JUNE 14-19, 2003 — UNIVERSITY OF MINNESOTA, MINNEAPOLIS, MN

The University of Minnesota, Center for Bioethics is pleased to host the 20th in a series of Institutes that have been held around the world. This unique conference is devoted to providing a foundation for extension personnel and faculty in the biological, agricultural, and environmental sciences to incorporate bioethics into their courses and extension activities.

Topics
Teaching Life Science Ethics Using Active Learning; Ethical Theory; How to Write Case Studies; Ethics and Animals; Genetic Engineering; Research Ethics; Bioethics Online; Environmental Ethics

Eligibility
Life science faculty and extension personnel at all colleges and universities in the U.S. are eligible. Travel and development awards are available. For details visit www.bioethics.umn.edu/News/bi2003/index.shtml

Registration
Registration for qualified applicants is free. For information about eligibility for travel and development awards and application materials visit: www.bioethics.umn.edu/News/bi2003/index.shtml

For more information
Contact the Center for Bioethics at 612-624-9440; Fax 612-624-9108; Email: bioethx@umn.edu; Website: www.bioethics.umn.edu.

The Institute is sponsored and funded by the United States Department of Agriculture & The National Agricultural Biotechnology Council.
How much weight should small differences in survival rates be given in allocating scarce organs? This question is even more significant because the UNOS data that is used to estimate mortality and survival has all the limitations of large national databanks. It is incomplete and at times inaccurate. In addition, large analyses fail to account for significant mortality variability among various transplant centers. The UNOS data is the best national data that we have. However, given its limitations, how much weight should we give it in influencing the allocation scheme?

Finally, various disease categories will fare differently in such a system. Diseases where patients are younger like cystic fibrosis will likely receive a greater proportion of lung transplants than diseases that affect older patients. Is it morally significant that categories of diseases will receive different treatment in this allocation scheme? Are advocacy groups for various disease categories right in claiming that their respective patients should be giving equal percentage of organs?

Ultimately, the critical goal for any allocation scheme is to find a balance between efficacy and urgency. Only then can such a system withstand public scrutiny and foster public trust. Reasonable people will disagree about how to define a just system and how to go about devising a new lung allocation model. What is clear is that the current model is arbitrary. Unfortunately, without further deliberation, research and statistical modeling the new system may not be much better.

Proponents of the new model claim that anything is better than the old system and that we should try the new system and see how it goes. Such arguments aren’t accepted elsewhere in medicine and so ought not be accepted here. In the practice of medicine, we have long followed the tradition of “first do no harm.” Therefore, we do our best to practice evidence-based medicine through years of painstaking research. Responsible formulation of health policy should follow the same logic. I agree that the current lung allocation system is far from perfect. However a system that primarily focuses on reducing waitlist mortality will ultimately result in net number of patient life years lost because organs are not used for maximal utility. As the practice of medicine tries to rely on evidence, so should the practice of health policy. The proposed new system must undergo further research prior to being instituted. A new allocation system must give equal consideration to reducing mortality as well as increasing utility.

Visit our website at www.bioethics.umn.edu

The Center for Bioethics website includes:

- Information on graduate studies in bioethics, course offerings, and other educational programs
- Center faculty descriptions and their research interests
- Current and past issues of the Bioethics Examiner and CNN.com Ethics Matters columns
- Annual Reports
- Reading Packets
- Upcoming events and announcements
- Minnesota Network for Healthcare Ethics Committees (MNHEC)
- Links to other bioethics resources

Organ Donor Data

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Recent Faculty Publications

**BOOK CHAPTERS**

**ARTICLES**

Tauer C. Central Ethical Dilemmas in Research Involving Children. *Accountability in Research* 2002;9(3-4):127-142.

Center Publications

**READING PACKETS**
Center packets contain an overview of legal and ethical issues, key articles, and a bibliography.

Organ Transplantation (August 1997)
Withholding or Withdrawing Artificial Nutrition and Hydration (July 1997)
Termination of Treatment of Adults (September 1997)

Distributing Limited Health Care Resources (April 1997)
Resuscitation Decisions (June 1997)
The Determination of Death (May 1997)
New Frontiers in Genetic Testing and Screening (August 1999)
Human Stem Cells: An Ethical Overview (December 2003)

**ANNOTATED BIBLIOGRAPHY**
Ethical Issues in Managed Care (1997) — articles addressing ethical issues in managed care.

Reading packets are available for $5 each. All orders must be prepaid. To order, make checks payable and mail to: Center for Bioethics University of Minnesota N504 Boynton 410 Church Street SE Minneapolis, MN 55455-0346

All packets are available on the Center’s website at www.bioethics.umn.edu.
Calendar of Events

May 9
Jeffrey Kahn, PhD, MPH, will speak on “Where Are We Going in the Human Genome Project?” at the University of Minnesota, Center for Bioethics Seminar Series, Minneapolis, MN. For information, contact the Center for Bioethics.

May 13
Steven Miles, MD, will speak on “Physical Health of Immigrant Elders” at the Health Advocates Group, St. Paul, MN. For information, email: pohmans4238@msn.com.

May 16
Jeffrey Kahn, PhD, MPH, will speak on “Protection vs. Access: Navigating the Ethical Tensions in Clinical Research” at the Park Nicollet Symposium, St. Louis Park, MN. For information, call 952-993-3531.

May 23
Jeffrey Kahn, PhD, MPH, will speak on “Bioethics and Pharmacogenetics” sponsored by University of Minnesota-Duluth, School of Medicine, Duluth, MN. For information, email: dflahert@d.umn.edu.

Jun 5
Jonathan Kahn, JD, PhD, will speak on “Race-ing Patents: How Law and Commerce Created an ‘Ethnic’ Drug” at the Law & Society Association Annual Meeting, Pittsburgh, PA. For information, visit www.lawandsociety.org.

June 3-8
“21st Century Bioethics: Brave New World?” sponsored by Kennedy Institute of Ethics. For information, visit www.georgetown.edu/research/kie or email: kicourse@georgetown.edu.

June 13
Andrea Nicki, PhD, will speak on “Psychiatry and Feminist Virtue Ethics” at the University of Minnesota, Center for Bioethics Seminar Series, Minneapolis, MN. For information, contact the Center for Bioethics.

June 14-19
Bioethics Institute for Life Science Faculty and extension personnel will be hosted by the Center for Bioethics and held on the University of Minnesota campus. For information, visit www.bioethics.umn.edu or call 612-624-9440.

June 23
Jeffrey Kahn, PhD, MPH, will speak on “Swinging on the Pendulum: Ethics and the Shift from Protection to Access in Clinical Research,” “Ethics, Policy and Stem Cell Research,” and “Lessons from a Case of Genetic Medicine” at the University of Iowa, Iowa City, IA. For information, visit www.research.uiowa.edu/hso.

Aug 4-8
Summer Seminar in Healthcare Ethics, sponsored by University of Washington School of Medicine, Department of Medical History and Ethics. For information, call 206-616-1864 or email: mbarnard@u.washington.edu.

“Medical Futility: How Much is Too Much?”
September 19, 2003

The St. Croix Valley Health Care Providers Ethics Advisory Committee is hosting a day long conference at Boutwell’s Landing in Stillwater, MN from 8:30 am – 3:00 pm. The Minnesota Network of Healthcare Ethics Committees (MNHEC) is co-sponsoring this event. For more information, call 651-430-4548 or email kimb@lakeview.org.
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Jonathan Kahn, Editor

The September 2003 Bioethics Examiner submission deadline is August 1, 2003.

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