



Organ Shortage: A Major Obstacle for Transplantation

ARNOLD G. DIETHELM, 1991–92

I am very appreciative of the privilege to have served as your president during the past year and accept this recognition on behalf of my colleagues at the University of Alabama and the Department of Surgery. I am very grateful to Dave Sutherland for his advice and assistance and to the members of the Council. I would particularly like to thank Mark Hardy, Marc Lorber, and Hans Sollinger. All transplant programs, to be successful, require a strong support base of support by surgeons, nephrologists, tissue typers, research technicians, and others. Our program is no exception, and I would like to particularly thank Drs. John Curtis, Bruce Julian, and Robert Gaston in Nephrology and Drs. Henry Barber, Mark Deierhoi, David Laskow, Steven Poplawski, and Dinesh Ranjan in Surgery. I would especially like to remember Dr. Bruce Barger, director of the Histocompatibility Laboratory, who died of cancer a few months ago. Bruce, a member of the Department of Surgery, built a superb laboratory with outstanding people. He will be greatly missed.

I would like to discuss with you today a subject that appears to me to be an obstacle of major proportions to clinical transplantation and especially to the transplant surgeon. The obstacle, directly in the path of clinical transplantation, is the major limitation to providing appropriate care to patients with end-stage organ failure. Unfortunately, the problem is not as exciting and scientifically challenging as the subject of tolerance, the mechanisms of allograft rejection involving cytokines, adhesion molecules, antigen presenting cells, and the like. In spite of what might appear to be a mundane subject, it is so critical to patient care that I find it reasonable to at least raise that subject with you and hope that the following brief review may provide a platform for further discussion. The comments will only reflect my thoughts about the matter, and if in conflict with others, I would be pleased to review the controversy with each of you.

Clinical transplantation, as we all know, is dependent upon immunosuppression, histocompatibility testing, organ preservation, and procurement. Fortunately, the

spectacular development of new immunosuppressive agents has increased living related donor transplantation at one year to more than 90% with the one haplo-matched recipient, 97% with the two haplomatched recipient, and from 78% to 85% with the cadaver recipient. These results are of course transplant center dependent. The role of organ preservation with University of Wisconsin (UW) solution has had a major impact upon the quality of organ function and greatly simplified the logistics involved in the operative procedures.

The experience in renal transplantation at our transplant center exemplifies that which has occurred in all other centers. As the number of transplant operations increase, the mortality and morbidity of the operation and postoperative care decreases. This quite properly increases the optimism about the possibilities of transplantation and in turn expands the spectrum of recipient patients suitable for organ replacement. All of this increases the number of patients awaiting transplantation and leads me to the subject of today—"Organ Shortage: A Major Obstacle for Transplantation." This problem to a large degree is the result of the scientific accomplishments of transplantation, both clinical and research.

Much has been said about the shortage of organs in the last few years, and I fully recognize that a solution will not be forthcoming today. We—the transplant surgeons—are by nature optimistic individuals and look to the future with enthusiasm. Although our scientific efforts are in general based upon a growing foundation of sound immunologic data, the same is not true with the organ shortage. In this area we must contend with social issues, ethical concerns, moral and religious views—none of which are really based upon the type of scientific data we are accustomed to analyzing. It is difficult to create a P value or develop a Kaplan-Meier curve upon all of this, although we have tried to do so at one time or another. It is even more difficult to ask, or worse yet assign, a young energetic surgeon to spend 10%, 20%, or 30% of his time to increasing organ donation. First, few deans of a medical school or members of a faculty promotion committee would look favorably upon this as "scientific accomplishment." Second, a steady diet of this sort of effort soon becomes tedious.

The potential role of xenotransplantation with or without transgenic animals is exciting to say the least. However, clinical application of xenotransplantation is in the future, and we as surgeons must deal with patient care problems as they exist currently. We can anticipate the future, but must live in the scientific world of today. In the next 15 minutes I will review some aspects of the organ shortage and offer a few suggestions.

Required Request

As a result of the nature of the problem, we transplant surgeons, as a group, have been much in favor of the "quick fix" solution. A reasonable attempt in this regard was the Required Request Law, part of the National Transplantation Act of 1984, which stated that all people entering a hospital were required to provide a statement—yes or no—as to whether or not they wished to become a donor if things didn't work out well. Furthermore, if the patient died, the physician in charge was required to ask the fami-

ly if they wished to donate the organs and tissue of the deceased patient. The concept is simple but has had little, if any, impact upon increasing organ donation. The reasons for the failure of Required Request are quite straightforward.

First, the public as a whole was not adequately educated on the subject of organ donation and had some concerns about the possibility of a premature decision of brain death by the physician. Brain death, a medical concept based upon sound neurological data, is still a bit uncertain to the general population. This level of patient uncertainty could and should be remedied by expanding public understanding of the entire subject, but progress has been slow.

Second, is the matter of consent or who “owns the body.” The next of kin frequently expresses the opinion, in no uncertain terms, that they want the deceased to be “buried whole.” In case any of you are not certain as to the meaning or intent of this statement, you need to see the facial expression of the next of kin who provides this information to you when you ask for organ donation. There is very little room for further discussion.

The third reason contributing to the lack of organ donation is based upon physician apathy in asking the next of kin for organ donation. The attending physician is often uncomfortable about the subject, may know little about it, may be discouraged about the death of the patient, and therefore avoids asking the question. Unless the next of kin thinks of organ donation, the patient will be pronounced dead without any request for organ donation and will be “buried whole.”

Presumed Consent

Unless the patient signs a donor card, has a living will, or has expressed personal feelings about the subject of organ donation to family or friends, he or she will have nothing to say. The subject will be raised when the patient is no longer able to express an opinion. Thus, the real question is “who owns or is responsible for the body?” In some circumstances no one comes forward and the answer should be simple—but legally can be complex. If one wishes to use the “presumed request approach,” this will only raise the ire of the next of kin—the very group who will cause the most trouble if society presumes to tell them what to do with the body of the deceased. The success of “presumed consent” for organ donation that has been noted in European countries may not be forthcoming in the U.S. It should be examined in much detail before being considered. Another approach is to initiate a law that all deceased persons should have their bodies willed to science. My guess is this will never pass muster.

Recipient Limitation

Logic might lead us to conclude that if the organ supply is limited and less than the patient demand, one solution would be to restrict or even reduce the patient demand for the organ. This implies some form of artificial guidelines to be placed upon the selection criteria for the recipient patient. This might include age (e.g., transplant patients only within a certain age range) or certain diseases (e.g., diabetes, lupus, or

focal sclerosis, all of which may recur). Another consideration would be to limit patients to one or perhaps two transplants. This is an artificial notion and one which I believe should be avoided until every other option has been shown to fail. This approach will entangle the transplant surgeon and the patient in a hopeless web of ethical and legal concerns which will not be beneficial to the patient or the field of transplantation.

Financial Incentives

Organ payment to the next of kin has been suggested as a means to increase organ donation and has been used in other countries with varying degrees of success. Fortunately in the U.S. payment for organs is prohibited by law. Another idea—now under study—is a means of compensation in the form of an insurance policy paid to the family for those members who die and donate organs. This at first glance may appear to be of benefit in expanding the donor pool. My guess is it will be another “quick fix” and create some insoluble problems. For example, two teenagers are in a car accident; both eventually become brain-dead, but one does so in 48 hours and the other in 21 days. Both families agree to organ donation. The patient with brain death in the first 48 hours is an excellent donor, while the second has a septic course and is unsuitable as a donor. The first family receives financial compensation while the second family receives none. The discrepancy is obvious. The use of financial incentives is a complex subject with many ramifications touching upon legal and ethical considerations and should be examined thoroughly. This approach may offend those families who believe in the altruistic approach.

Up to this point I have presented to you the problem of organ shortage, its impact upon organ transplantation, and a few proposals to remedy the situation. None of them, individually or collectively, I believe, will be of great help and some could have a negative influence. At the risk of returning to a simplistic concept than is well known to all of you, I would like to suggest another method to improve the situation. It is not a “quick fix.” The idea is not new, not a brain-storm, and requires no new laws. It will require a variety of people to participate with help from the churches, government, the state, private enterprise, and local civic groups. This help is in the form of *education*. This includes education to people of all ages in many places, such as schools from 9th grade to and through college and postgraduate education, places of employment, worship and community groups. The education will include information on the clinical need and benefits of transplantation. It should emphasize that organs cannot be made or purchased—only donated. The public must be made aware of the valuable resource of human organs and tissue, and constantly reminded of the lives that can be saved by the giving of organs. Above all we will need help from private enterprise in terms of ideas and their implementation as well as some financial support. Perhaps a national campaign similar to “buckle up,” improved nutrition with a decrease in cholesterol intake and the antismoking efforts would enhance public awareness. The problem with this approach is that it will take time—at least five or possibly ten or fifteen years from the starting point, and the question is can or will we sustain the effort.

As I mentioned earlier, we as surgeons, especially in the field of transplantation, are impatient and by nature interested in “quick fix” solutions. This proposal is not in that category. Rather it is a long-term investment for a very good cause based upon public education and altruism. It is possible that the government at both the national and state level might be willing to undertake to participate in such an effort, combined with the transplant community and with selected members of the business community. I am quite convinced that we as transplant surgeons have neither the time, expertise nor desire to undertake the task alone. The first step would be to encourage 30 to 45 minutes a year to be devoted to the importance of organ donation in schools including grades 9 through 12. This could be accomplished with the use of video presentations and followed up by the willingness of students to sign donor cards with their families, recognizing it is only an expression of their desire, not a legal document. In four consecutive years all high school students and college students would have the opportunity to express their opinion, and if negative at an early age, perhaps convert their decision to a positive one. Whether or not a donor card is a legal document seems unimportant. What is important is that a conscious decision was made and expressed in writing by the individual. Rarely, in my experience, has a donor card request been disregarded by the family. This simple concept of donor card signature is based upon two features: altruism and education.

Request for Donation

The most common cause for failure of organ donation is the inability to receive consent from the family. The individual or individuals requesting organ donation are key in obtaining permission from the family, and their approach and sensitivity to the subject is often central to receiving approval. If those asking for permission for organ donation are insecure, uncomfortable, or perhaps even negative, it will be unlikely that a positive response from the next of kin will be forthcoming. Thus, a team including nurses, procurement coordinators, clergy, transplant recipients, and physicians might be especially helpful. This would be called a request team; one or two members would visit the family. Such a team would include representatives of minority groups who would be sensitive to the religious and ethical beliefs of the family. They would have special training in methods of asking for donation and would be available 24 hours a day to assist in the request to the family. The request team therefore would be a combined responsibility of chaplains, physicians, nurses, and other hospital personnel. This request team might increase family consent and avoid the consequences of physician apathy.

As I mentioned at the beginning, organ shortage is not a scientific problem but a public health problem. We surgeons, nephrologists, and physicians will need support from various groups. At least with a broadly based program of education, we are on firm footing and, if carried out in good taste, should not be offensive. At the very least the expanded role of public information should do no harm, avoid new laws and, over a period of time, might be helpful. Altruism remains the cornerstone of organ dona-

tion in this country. A widespread national education program combined with the altruistic attitude of the public will be a sound base for expanding organ donation.

As a final comment, physicians as a group and surgeons particularly are often uncomfortable about the overlap of science and medicine with ethics. In closing, I would like to read a quote of Karl Popper published by Peter Medawar in *The Limits of Science*.

“It is important to realize that science does not make assertions about ultimate questions—about the riddles of existence, or about man’s task in this world. This has often been well understood. But some great scientists, and many lesser ones, have misunderstood the situation. The fact that science cannot make any pronouncement about ethical principles has been misinterpreted as indicating that there are no such principles while in fact the search for truth presupposes ethics.

—Karl Popper, *Dialectica* 32: 342

Thank you again for the opportunity to be your president.