Irreversible failure of a major organ such as the heart, lung, or kidneys is relatively rare in adolescence. Fine, for example, estimates the annual incidence of end stage renal disease among infants, children, and adolescents at three new cases per million of the total population. Although organ transplantation for most adolescents no longer involves overwhelming technical problems, serious psychosocial and moral issues frequently arise. This article will examine some major moral issues in organ transplantation for adolescents. As did an earlier article on organ transplantation in children, it will use basic moral principles of beneficence, autonomy, and justice as a framework for discussion. Applying these basic moral principles to adolescents will show how their care raises issues different from that of both young children and adults.

The severe stress of a catastrophic illness occurring at a complex period of development can pose difficult problems for adolescent patients and their caregivers.

BENEFICENCE

The principle of beneficence, which has had a prominent place in medical oaths and codes since antiquity, enjoins physicians to act for the benefit of their patients. To apply this principle, of course, physicians must decide what kind of care will, on balance, serve the best interests of their patients.

The nature of the benefits sought through organ transplantation and the probability of achieving them vary somewhat with the type of organ to be transplanted. Liver, heart, and heart-lung transplantation, for example, offer the prospect of prolonged life and a return to normal or near normal activity for debilitated...
continued from page 246 and otherwise terminally ill patients. The number of these procedures and their overall success rates have increased dramatically in the last five years since Food and Drug Administration (FDA) approval of the immunosuppressive drug cyclosporine. Kidney transplantation, although not life-saving in the strict sense, has a number of potential advantages over chronic dialysis for adolescent end stage renal disease (ESRD) patients, including better quality of life, avoidance of a complicated treatment regimen, increased rehabilitation potential, and possibly increased growth potential. For these reasons, the number of kidney transplants has increased dramatically over the last decade, and one author has called renal transplantation the only realistic treatment choice for older children and adolescents with ESRD. Often used in conjunction with renal transplantation, pancreas transplantation can normalize glucose metabolism and thereby prevent severe secondary complications of diabetes, such as kidney failure and blindness.

All of these benefits notwithstanding, however, organ transplantation also poses a number of serious risks. Foremost among the short term risks of organ transplantation are surgical complications, infection, and acute rejection of the transplanted organ. Although the refinement of surgical techniques and improved immunosuppressive drug regimens have reduced these risks substantially in recent years, one fourth to one third of children receiving liver and heart transplants still die within a year after surgery. The late complications of organ transplantation, mostly due to long term immunosuppressive therapy, include infection, chronic rejection, several types of cancer, coronary artery disease, bone disease, hypertension, nephrotoxicity, cataracts, altered physical features, and stunted growth. Some of these complications are clearly life threatening and require repeat transplantation; others are psychologically disturbing, especially for adolescent patients sensitive about their physical appearance.

Organ transplantation is a recognized form of advanced therapy for patients with end stage organ failure. For the majority of adolescent patients, the prospect of a longer and more nearly normal life offered by transplantation is clearly preferable to the alternatives of death or chronic dialysis. For a few adolescent patients, however, organ transplantation may not be, on balance, a beneficial treatment. In two recent reviews from pediatric nephrology programs, for example, authors report that they do not generally recommend severely retarded ESRD patients for renal transplantation. One report offers the following rationale:

It has been our feeling that such children (IQ less than 40), who require custodial care, should not be subjected to the rigors of dialysis and renal transplantation. A child with this
degree of mental retardation cannot comprehend the various procedures required for undertaking such a therapeutic regimen and therefore will adapt poorly to the treatment regimen.20

This passage suggests a judgment that the severely retarded patient, due to an inability to comprehend the demands of treatment or tolerate its discomforts, will be less likely to have a successful transplant and that whatever prolongation of life is achieved may not be experienced as beneficial by the patient. If the patient’s quality of life is already significantly diminished, the likelihood of prolonging life may not justify the infliction of significant pain and suffering.

A similar weighing of benefits and burdens would be required to determine the best interests of any severely compromised patient. Consider a previously transplanted adolescent patient with severe complications of immunosuppressive therapy, deteriorating allograft function, and only limited prospects of a successful second transplant. At some point the likely burdens of transplant surgery would outweigh the anticipated benefits for such a patient. When that point is reached, the physician’s commitment to benefit the patient, or at least to do no harm, dictates a treatment plan without transplantation.

Questions have also been raised about the advisability of offering transplantation to patients who have a history of noncompliance with treatment regimens.19,20 Schroeder and Hunt identify medical compliance as one of five primary indications for heart transplantation.21 Noncompliance appears to be a particular problem in adolescent patients due to their dissatisfaction with the cosmetic side effects of immunosuppressive therapy and with their dependence on medical care, caregivers, and parents.4 Unless adherence to immunosuppressive therapy can be achieved, the transplanted organ will eventually fail and the benefits of transplantation will be lost. In some cases, therefore, physicians may conclude that a noncompliant patient will not benefit from transplantation.

AUTONOMY

In addition to potential benefits and burdens, transplant decisions depend upon other factors as well, including patient wishes and the need to allocate a resource for which the demand far exceeds the available supply. These factors raise questions of autonomy and justice.

Whoever weighs the relevant benefits and risks, choosing whether to undergo a major surgical procedure such as organ transplantation is clearly a momentous decision. Who should make that decision? A second moral principle, that of autonomy, suggests an answer to this question: it ascribes to competent persons the right to choose and act freely, especially in those matters most closely affecting their own lives. A fundamental principle in modern ethical theory and in the American political system, individual autonomy or freedom is also recognized in the medicolegal doctrine of informed consent. The doctrine of informed consent is designed to give patients greater control over their medical treatment by directing caregivers to obtain the patient’s consent prior to treatment. To be valid, this consent must satisfy three conditions.22 First, the patient must be mentally competent, i.e., must have the ability to make a meaningful choice. Most younger children lack this ability and thus their parents, as their natural guardians, are authorized to make treatment choices for them. Second, the patient must be adequately informed about the proposed treatment, including projected benefits, risks, and possible alternatives. Finally, the patient’s decision must be made freely, without undue pressure or manipulation.

Although a moral and legal consensus supports the right of competent adult patients to informed consent and the right and responsibility of parents to consent to their younger children’s health care, the situation regarding adolescent patients is less clear-cut. According to the traditional view, all minors were legally incompetent and hence consent for treatment had to be obtained from their parents or legal guardians. As Holder points out, the law has recently given greater authority over medical decision making to adolescents by means of minor treatment statutes and the concepts of the mature minor and emancipated minor.23 These legal doctrines evolved out of a growing recognition that many adolescents have a great interest in choosing their own health care as well as the capacity to understand medical information and arrive at reasoned decisions.

Brock has recently applied an analysis of the concept of competence developed by the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical Research to the case of children.24 According to that analysis, decision making capacity (competence) requires three elements: (1) possession of a set of values and goals; (2) the ability to communicate and to understand information; and (3) the ability to reason and to deliberate about one’s choices.”221p977)
For both adolescents and adults, decisions about competence should depend on the abilities of the individual patient, the complexity of the decision at hand, and the consequences of a particular choice.

Based on a review of the psychological literature, Brock concludes that most children by age 14 or 15 possess these three elements to a degree roughly comparable to that of most adults. He also points out several differences between the circumstances of adolescents and adults, however. Although adolescents do possess a set of values and goals, these may change in predictable ways as they mature into adulthood. For example, concerns about physical attractiveness may play a much more dominant role in adolescence than adulthood. When such concerns about appearance motivate a life-threatening decision to discontinue therapy, caregivers may want to intervene to protect an adolescent’s long term interests. Also, adolescents, unlike adults, usually have parents with a deep concern and significant responsibility for their welfare. Insofar as adolescents remain dependent on their parents for support, parents have a strong claim to a voice in, if not total control over, important decisions regarding their child’s health care.

For both adolescents and adults, Brock argues, decisions about competence should depend on the abilities of the individual patient, the complexity of the decision at hand, and the consequences of a particular choice. Thus, a patient with somewhat limited abilities may be competent to make simple but not complex health care decisions, and may be competent to consent to but not to refuse a life-saving treatment.

How do these considerations apply to adolescent organ transplant candidates? Ganofsky, Drotar, and Makker report a number of severe psychosocial crises among their adolescent ESRD patients, including episodes of untruthfulness, depression, and regression. These authors stress the importance of building continuing relationships with young patients and offering support while also encouraging independence and maturation. Such long term relationships foster trust and enable caregivers to share decision making authority gradually as patients grow in their ability to accept it. In a related context, Nitschke et al report good results with a policy of actively involving children and adolescents in choosing between experimental and supportive care to treat their advanced cancer. These researchers concluded that children over age five seemed to comprehend the finality of death and were able to make rational decisions about therapy.

Despite episodes of anger, depression, and regression, therefore, the developing understanding and autonomy of seriously ill adolescent patients cannot be ignored. Rather, caregivers must attempt to match responsibility with individual capacities in order to encourage and respect the adolescent’s sense of autonomy and self worth.

If adolescents can choose to receive a donated organ, can they also choose to donate a kidney to someone else? The answer to this question is less clear than that of participation in decision making by adolescent organ recipients for two reasons. The potential benefits to the donor of giving up a kidney, such as preventing the death of a family member, are indirect and often tenuous at best. Thus, given the pain and small but real risks of organ donation, it is not usually obvious that donation is in the best interests of the donor. In addition, the psychological pressures surrounding organ donation and transplantation can be powerful and complex. This may prove especially true for adolescents who are still very dependent on parental guidance and support. These considerations suggest the need for strong efforts to protect potential kidney donors, especially adolescents, from exploitation or coercion. Nevertheless, in several follow-up studies most organ donors, including adolescents, report great satisfaction about their decision to donate. Moreover, as Fost points out, even children’s decisions about organ donation seem no less informed or voluntary than those of adults, although neither are models of informed consent. As with organ recipients, then, decisions by organ donors should be evaluated individually with special attention to helping potential donors understand what is at stake and make an autonomous, unpressured choice.

JUSTICE

Even with living donors and concerted efforts to procure cadaver organs for transplantation, the number of organs available each year in the United States falls far short of the number needed. How, then, should this limited number of available organs be distributed among potential recipients? For those who are fortunate enough to receive an organ transplant, projected medical expenses range from $25,000 for a kidney to as much as $938,000 for a liver. Who should bear these costs? Is payment for organ transplantation a justified use of public funds?

These difficult questions raise issues of distributive justice; they involve judgments about the proper distribution of social and economic benefits and burdens among the various members of a given population. As noted in a previous article, no clear consensus has emerged in the United States regarding the proper continued on page 252
continued from page 250 principles of distributive justice or the just allocation of resources for organ transplantation, and this coverage varies widely among public and private insurers. The major exception to this variability is end stage renal disease, where a categorical federal program established in 1972 pays most of the costs of dialysis or transplantation for all patients. 12 Schwartz has attributed the continuing rise in health care costs primarily to new high technology, high cost therapies, including organ transplantation. 13 If this is the case, growing pressures for medical cost control may eventually result in greater regulatory or price restrictions on the number of transplants performed. Kidney transplantation, however, appears to be a much more cost-effective treatment for ESRD than chronic dialysis. 10

Organ transplantation is already limited, not only by its costs but also by the number of organs available from cadaver donors. Significant progress has been made in recent years toward the establishment of a national policy for the allocation of donated organs. Congress passed a National Organ Transplant Act in 1984 that authorized the creation of a National Organ Procurement and Transplantation Network to coordinate the activities of regional and local organ procurement agencies and transplant centers. 6 A contract to establish the National Organ Procurement and Transplantation Network (NOTPN) was awarded to the United Network for Organ Sharing (UNOS), and in 1987 UNOS implemented a national computerized system for matching donor organs with waiting patients. Modeled from a matching system proposed by Starzl et al., 14 the UNOS system for kidney matching awards points to patients for degree of HLA antigen match with the donor organ, length of time spent on the waiting list, degree of antibody presentimentation, medical urgency, and, when permissible, storage time is short, the proximity of the organ to the patient. The organ can then be offered to the patient with the highest total number of points. One exception to this multifactorial system is the requirement that a kidney be offered to any patient who has a perfect six antigen match with that organ. 15 A slightly different matching system has been developed by UNOS for other organs.

Starzl et al. presented their point system as an "objective method" that could eliminate ad hoc case selection based on incomplete information. 14 Salviatierra has described UNOS policies in this area as efforts "to ensure the equitable allocation of donated organs and to preclude favoritism based on political influence, race, sex, or economic status." 13 Because it provides a standardized and public method for ranking patients, primarily on the basis of unambiguous factual information, this system for allocating donor organs does eliminate most of the potential for individual bias.
Value judgments do play a role in the structure of the system, however, in deciding which factors to include in the system and how heavily to weigh those factors in relation to one another. Factors include in the present system owe their significance to several different reasons: the desire to achieve a successful transplant (HLA matching and proximity of organ and recipient), the desire to prevent death (medical urgency), and the desire to give every patient an opportunity to receive a transplant (waiting time and presensitization). Although each of these factors and reasons is arguably legitimate, the decision to include just these factors and no others, and the specific weight assigned to each of them, are necessarily somewhat arbitrary and open to question. Fryd argues that giving priority to patients with high levels of presensitization may lead to a decline in the overall success rate of renal transplantation since these patients, many of whom have already had one or more failed transplants, are less likely to be successfully transplanted on subsequent attempts. 22 Thus, two of the grounds for allocating organs, namely maximizing the benefits of successful transplants and maximizing individual access to transplantation, may not be completely compatible, necessitating a decision about which one should be given priority.

Finally, those concerned with facilitating transplantation for adolescent patients might propose that matching systems award extra points to patients below a certain age, such as 20 years old. This proposal might be defended on the grounds that these young patients will probably live and therefore benefit longer from a successful transplant and, in the case of ESRD, that children and adolescents are much less able to manage and tolerate dialysis than adults. Mendez points out that one of the goals for transplant policy noted in the 1984 National Transplant Act was concern for children. 23 Making age a criterion in the matching system could address this concern.

Opponents of this proposal might argue that patient age is more a social than a medical factor. Including it, therefore, opens the door to other social considerations and threatens the ideal of equal access to the benefits of transplantation. Some age-based criteria are already widely relied upon, however, since patients above a certain age are rarely considered candidates for transplantation. More data comparing the outcome of transplantation in adolescents and adults may be necessary to resolve this issue convincingly.

In any case, despite some unavoidable arbitrariness in the system, the advantages of having a decision making process that can be publicly stated, defended, and reviewed as well as consistently applied argue strongly in its favor. As data from its operation accumulate, the system can be revised in order to approach more closely its goals of equitable and efficient allocation of donor organs.

REFERENCES