Cardiac transplantation: a psychological perspective

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FOR MOST PATIENTS and families, the psychological stresses and adjustments associated with cardiac transplantation originate not during the process of transplantation itself but with the discovery of life-threatening illness. Their responses and coping mechanisms frequently reflect the stages described by Kubler-Ross: denial of the severity of illness and a search for better physicians or treatment, anger at fate for being randomly victimized by heart disease or for membership in a family with a history of early cardiac death, bargaining behavior such as impeccable dietary compliance or exercise in the hope of reducing cardiac disability, and depression when nothing stops the progression of the disease.

When the onset of illness is gradual, changes in patterns of family interaction and role assignment often occur. An ill child may require a disproportionate share of parental attention and resources. Siblings experience jealousy and guilt while simultaneously having more difficulty in school and in relationships with peers. Parents’ feelings of helplessness because they are unable to make the child well may lead to occasional, painful skirmishes over whose “side of the family” contributed the genes that led to the illness.

If the patient is an adult, the range and magnitude of his or her contributions to the family are diminished. Loss of strength and cardiac capacity reduce parental ability to keep up with the activities of children. Family income may shrink, either through loss of the patient’s salary or through the de facto loss of previously discretionary income that is now used to pay medical bills.

Marital problems develop, particularly in recent marriages, if one partner perceives that he or she is now responsible for “taking care of” the other for an extended time. In reviewing notes from more than ten years of interviews with potential recipients and their families, I have found that almost all spouses in marriages of less than four years made at least one reference to “the person I might have married instead.”

**Initiation of transplant discussion.** The initiation of transplant discussion confirms for the patient not only that the physician can recommend no therapy other than cardiac replacement that would extend life, but also that the remaining life, of whatever quality, can be counted in months rather than years. Such discussion can come as a shock to the patient and precipitate denial, anger, and withdrawal as the patient adjusts to the finality of the proposal. It can also come as a relief. “We didn’t want to hurt Dr. J’s feelings, because he’s been our family doctor forever. But my wife and I have talked about transplants since my first heart attack. We were relieved when he brought it up.” Transplant discussion today is begun as commonly by patients and families as by the attending physician.

Prior knowledge of transplantation and the hope it offers, however, often hides a lack of understanding of transplant limitations. During a recent meeting, I was told of the number of hospitals performing transplants in a two-state area. When asked about survival rates and postoperative complications, the informer was taken aback. “I don’t know. You almost never hear anything after they announce the transplant. I presumed they were all doing fine.”

Recognizing this lack of understanding can be critical to physicians and transplant groups providing care to potential recipients. Emotional support and information designed to reduce anxiety are appropriate for many patients. Yet, the teaching involved in patient selection and informed consent may greatly increase distress for some who were initially enthusiastic. “I was so glad Carl didn’t need a transplant years ago when everyone died. Now you’re telling us some people still die after the surgery. You sure don’t publicize that, do you?”

**Selection of recipients.** Initial screening for cardiac transplantation typically involves the transfer of patient medical records and a psychosocial history to the transplant center. Objectives of this review are to identify those patients for whom further work-up is war-
ranted and to avoid unnecessary travel and hospitalization for those for whom transplantation is clearly contraindicated.\textsuperscript{2} The review also provides sufficient information to allow psychosocial as well as medical care to be individualized if the patient comes for evaluation.

If the transplant center is distant from the potential recipient’s home, a telephone call from the social worker or cardiologist helps assure the patient that the transplant group is human.\textsuperscript{3} If the patient is transferred from another hospital, communication of emotional and medical status reports between staffs is crucial.

The evaluation process is inherently stressful for both patient and family. It is specifically designed (1) to assess whether the patient has a reasonable hope of surviving cardiac replacement and achieving satisfactory rehabilitation, and (2) to share with the patient and family sufficiently honest information to allow them to make an informed decision as to whether to proceed with the surgery.

Outcomes of the medical evaluation range from identification of alternate therapy to the determination that coexisting medical problems preclude transplant survival. The psychosocial or psychiatric evaluation may reveal excellent social supports and patient understanding of the procedure and lay the foundation for a continuing supportive relationship between the patient and family and therapist. It may document problems such as substance abuse or noncompliance that are severe enough to exclude the patient from transplant candidacy.\textsuperscript{4–7}

The response of most patients and families is a combination of realistic anxiety and a concerted effort to please and convince the “gatekeepers” that transplantation should be approved. The patient is described as having not only the usual requirements but also exceptional characteristics that would enhance survival. A serious risk is that the patient will feel compelled to downplay his fear and uncertainty.\textsuperscript{4} Or, if unidentified, caregivers’ own desires to believe in the efficacy of transplantation may hinder their ability to hear and accept realistic patient fears.

Patients who come for evaluation often begin by explaining that they have “things left to do” and by expressing a desire for “more time” to spend with loved ones.\textsuperscript{7} When encouraged to talk, they present a poignant list. “My first grandchild is due in August. I can’t bear the thought of dying before I hold the baby.” “My son is starting quarterback for the UCLA football team. It’s my alma mater. Get me to Homecoming and I’ll die a happy man.” “My children are two and three. If I die now, they’ll never be able to remember that I was their mother. Please let me have just a few more years.”

If the patient behaves “poorly” during the evaluation, either with respect to medical compliance or interactions with staff, the diagnostic problem is more complex. “If [serious cognitive dysfunction] is present, a complete neurological evaluation... should be carried out to rule out irreversible organic brain disease, which would contraindicate transplant surgery.”\textsuperscript{8} In some instances, the onset of illness may simply be so recent that the patient has yet to work through the resulting denial and anger. In others, particularly if the behavior is incongruent with the patient’s history, the patient or family may be using the only means they can find to avoid or express ambivalence about transplantation.\textsuperscript{4, 6–8} A thirty-four-year-old art teacher with familial cardiomyopathy was referred for evaluation.

Medical reports described good compliance, he had two small children, and staff looked forward to his arrival. His hospital behavior, however, alternated between yelling and withdrawal. Laboratory work was refused. When asked what could help, he explained tearfully, “I’ve always known I’d die young. I know inside I wouldn’t survive the transplant. My wife wanted me to come, and when you scheduled me, I didn’t have the courage to refuse. Just let me go home and be with my children.”

\textbf{Informed consent.} In many ways, patient selection and informed consent are—or should be—inextricably interwoven. Informed consent requires that the patient have a thoughtful understanding of the risks, limitations, and on-going requirements of transplantation as well as the potential benefits. To the extent that the patient understands and accepts these realities, he is better able to participate in patient education, to trust staff members, and to engage in psychological preparation for the stresses that lie ahead.

The patient is also empowered\textsuperscript{9} to decide against transplantation, if he so desires, or to request more time to weigh the pros and cons before making a commitment. “The final goal of the transplant evaluation is not to persuade a ‘good’ candidate to choose surgery but to provide the necessary information and freedom through which the patient and family can reach the decision that is best for them.”\textsuperscript{10}

\textbf{Waiting for a donor heart.} Acceptance as a transplant candidate brings the possibility of death into sharp focus. The wait for an appropriate donor heart has perhaps been best described as “interminable.”\textsuperscript{11} Fear of dying before a donor heart is found is the predominant feeling of most patients. Even those who are stable enough to wait as an outpatient find themselves
fearful of leaving the house despite their beepers, unusually critical of family members' behavior, and increasingly withdrawn from superficial social relationships. Embarrassment and guilt are felt as patients realize they are paying close attention to reports of injury accidents and stopping all other activity when a siren is heard.

Hospital inpatients, despite their access to emotional support from the transplant team and committed, knowledgeable nurses, experience even greater difficulty because of the imminence of death. A primary care nursing model is often used to reduce stress for the patient and to enhance the development of trusting relationships. If anxiety or depression is severe, psychiatric consultation may be requested and mild sedation or hypnotics administered.

Emotionally supportive, regular contacts with the patient’s family, which are important under all circumstances, become especially significant if the patient requires critical care measures to sustain life. The challenge is to help family members prepare both for the possibility of the patient’s death and for the possibility of survival that may last from five to twenty years. Spouses often intersperse talk about funeral arrangements with plans for a family vacation after the patient comes home and expressions of despair that the situation is so unmanageable and uncertain. As long as the outcome is unknown, care must be taken that the family does not begin planning solely for the patient’s death, writing him out of the script for future activities and withdrawing from interaction and caring. Simultaneously, help must be offered with anticipatory grieving and with needed plans should the patient die.

The recent nationwide explosion in the number of centers performing heart transplants and the competition for a limited donor supply add to the patient’s stress and the family’s sense of helplessness and of “not doing enough.” Publicity given the need for a heart in exceptional instances, the Baby Jesse controversy, and the use of an artificial heart “bridge,” for example, lead other families to desperately wish that they too could gain the attention that appears necessary to ensure a heart. A recent newspaper article entitled, “Hospital Feud Explodes Over Transplants” described the competition among hospitals for two donor hearts. Almost invisible in the dispute were the feelings and lives of patients and families who are dependent on an insufficient flow of donor organs.

Transplant hospitalization. Hospitalization after cardiac transplantation can be separated, in terms of the psychological challenges faced, into three relatively distinct phases: (1) the immediate postoperative period, (2) the diagnosis and treatment of the first rejection episode, and (3) the “recovery” or later postoperative period that begins with control or resolution of the first rejection episode.

The immediate postoperative period is often described as a “honeymoon” period, “a time of relatively little stress,” or a time of euphoria. The threat of death before a donor heart becomes available is removed, and symptoms such as angina and shortness of breath disappear. The patient can competently judge his own improved circulation by the color of his extremities. The sense of helplessness, of being unable to do anything to extend life, is gone. Most recipients embrace patient education with enthusiasm.

This is also a time of relief and joy for families. Preoperative teaching and contact with other recipients and families have prepared them for the isolation requirements of the intensive care unit. Trusting relationships have developed with primary nurses and transplant team members. The terrifying balancing act between planning for the patient’s death and hoping for survival can at least temporarily be avoided.

Acute delirium is occasionally reported during this period, but more common subtle problems can be overlooked. Most recipients hope they will be among the rare patients free of rejection. For some, the need to repay the transplant group or to fulfill a bargain made with God during the wait for a donor will lead to promises to “dedicate my life to medical science” or to “help others as you all have helped me.”

Diagnosis of the first rejection episode almost invariably results in a brief period of depression. Thoughts of dying return along with feelings of helplessness, of being unable to control fate, or of being unable to be “perfect enough” in following medical direction to avoid rejection. The onset of rejection has always been perceived by patients as hidden and insidious. That perception can be heightened for cyclosporine-treated patients by the fact that rejection has no clinical signs or symptoms and can be diagnosed only by myocardial biopsy. Conventionally treated recipients, for example, often gain a sense of intellectual, if not physiologic, mastery by learning to calculate electrocardiographic voltage. Such coping mechanisms are not available to the cyclosporine-treated group. Patients may be less interested in learning about the biopsy technique, because of anxiety and inability to influence its results, than they are in mastering medications and prevention of infection.

For many patients and families, emotionally adjusting to the first rejection episode or threat thereof may be the last major psychological challenge on the path to
hospital discharge. The sobering event may lead recipients to assess that “they have traded one form of illness for another.”15 But it also demonstrates that rejection is treatable and may increase the patient’s commitment to carefully designed, detailed patient education programs.19, 20

During the predischarge period it is important to combine teaching and medical surveillance with an appreciation of the individual recipient’s skills and characteristics and to allow him to talk about the “things [he] wanted to do” if he were to survive the transplant procedure.17 It can be difficult for transplant team members to recognize (or to give up) the power they have assumed in a recipient’s life. Yet their capacity to show regard for the patient’s “nonillness” competencies and roles has a significant impact on the recipient’s self-confidence in approaching discharge and beginning rehabilitation.

Several years ago, a talented and frightened engineer was one of the first transplant recipients in a new intensive care unit. His medical condition improved rapidly after resolution of his first, relatively mild, rejection episode. His temperament did not. Much of his fury was directed at the “idiots” who designed the ICU. His points were taken seriously, and he was given the task of identifying improvements that could realistically be made. The recipient happily resumed his role as engineer; subsequent patients benefited from his recommendations.

Whether the recipient expresses eagerness or reluctance as hospital discharge approaches, the most common underlying feeling is ambivalence. The patient is apt to be in a city distant from his home and friends. His desire to resume certain roles within the family and his plans for “changes” may be at odds with the roles that family members have assigned themselves during the transplant period. The prospect of monitoring medications and side effects without nursing support may sometimes appear overwhelming.

A variety of approaches can be used to reduce the recipient’s fear and increase self-confidence. Hospital passes of increasing length confirm for the patient his ability to function without constant medical surveillance. Passes timed to coincide with family activities in which the patient is deeply involved reduce reentry shock while maintaining access to the transplant social worker or psychologist if problems arise. Activities listed as reasons for wanting the transplant (e.g., attending a child’s birthday party or a son’s or daughter’s wedding) are especially important in reestablishing the patient’s belief that he can function as a valued, healthy family member.

The recipient is introduced to the outpatient transplant coordinator20 and an orientation tour is made of the clinic that parallels the earlier orientation to the ICU. If the recipient is planning to return to school or work within the next few months, contact with an employer or school principal enhances the focus on rehabilitation and normal activities.

Death after transplantation. Obviously ignored in the preceding paragraphs are those patients who die after transplantation and their families. Usually the events leading to death are drawn out. Hope is interwoven with despair over an extended time. Rejection episodes appear to respond to treatment but then recur. Infections that are controllable in most recipients prove unmanageable in a few.21, 22

For the recipient who has already experienced the onset of life-threatening illness and the uncertain wait for a donor heart, stress is cumulative. Optimism fades, and with it often the patient’s interest in family and transplant-related activities. Anxiety, depression, and cognitive disorders present at a much higher rate than in patients whose postoperative course is uncomplicated. Watts et al.4 have described careful guidelines for the differential diagnosis and management of such symptoms, with particular attention paid to the range of medical and psychological factors that can contribute to their appearance.

For families, the need is again to balance hope for survival with realistic planning for death until the outcome is known. Gradually, the balance is tipped toward death. Plans for a funeral and notification of relatives are reactivated or completed. Family members may quietly ask staff to avoid or stop heroic measures to extend life. Physicians or nurses who are committed to the patient’s survival may receive small gifts from family members who are by now more accepting than they of the patient’s death. “I brought Dr. B breakfast this morning because he’s been staying up nights trying to keep Jack alive. We know he’s done all he can and it’s okay.”

When death occurs, grief and loss are acute, but they are coupled with a sense of relief and are shared openly with nurses and transplant team members who participated in the patient’s struggle for life. Support of other transplant families is valued,16 and there is a genuine wish that their loved ones fare better than the deceased. Families often reiterate that both they and the recipient understood the risks and would make the choice for transplant again under similar circumstances. While bereavement is not appreciably shortened by anticipatory grieving that occurs during the transplant process, there has also been nothing to indi-
cate, over the years, that interim balancing of grief and hope makes recovery from bereavement longer or more difficult.11

Transplant survival—the first six months. During the first few months after discharge, recipients are followed closely, usually in the outpatient clinic of the transplant center. Weekly biopsies are gradually tapered; manageable side effects of immunosuppressant therapy such as hypertension are controlled and monitored.23 Psychological problems and difficulties in family adjustment can be brought to the transplant social worker, psychologist, or psychiatrist, or they can be shared with fellow recipients in formal or informal groups if the patient or family desire.15, 18

Problems experienced by recipients and families during this time fall roughly into two categories: (1) symptoms and events that are common but disturbing and about which reassurance is sought from peers and/or medical personnel, and (2) problems of recipient or family adjustment that are related to preillness interaction as well as the transplant and for which individual or family counseling is appropriate. Side effects of drugs, responses of acquaintances and co-workers, and normal family disruptions are typically included in the first category. “I know they said I’d develop acne, but are you sure they meant this acne?” “My boss gets dramatic when he talks about transplant. I’d rather talk about work or football.” “The children sometimes act like I’m a visitor. Did yours do that at first?” Problems representative of the second group are more likely to include confrontations over who has control or power within the family or feelings of the nonill spouse or siblings that they now deserve the lion’s share of attention. Less commonly, but importantly, particularly if publicity is involved, the attention and recognition accompanying the transplant may have been very appealing to the patient or spouse. Efforts to help the patient to return to a “normal” lifestyle are actively resisted. Patient demands for extra attention and privileges gradually alienate clinic staff and family friends. One recipient temporarily terrorized staff by threatening to call his “new friend,” a television reporter, whenever his wishes were not met.

These problems can usually be resolved with counseling and sharing of feeling between recipient and spouse. Grievances that predate the transplant period may be resolved because the transplant has made family caring and communication more open. When short-term resolution appears unlikely or the problems are apt to recur, the recipient and family can be encouraged to seek therapy in their home community and to build on the trust established with the transplant group.

Long-term survival. As the frequency of clinic visits and biopsies diminishes, the energy and attention of most recipients and families shift from transplant-related tasks to family, vocational, avocational, and school activities. Patients who live at a distance from the medical center return home. Comfort and equilibrium are regained in family relationships and friendships. The likelihood that the recipient will begin a description of himself with “I am a transplant” decreases markedly.

Quality of life is good for most recipients whether defined by functional capacity, the ability to return to self-selected meaningful activities, or the reports of recipients themselves. Between 80% and more than 90% of survivors return to New York Heart Association class I cardiac status.21, 24, 25 Between 82% and 91% of recipients surviving greater than one year have been classified as rehabilitated in several studies of Stanford recipients.24, 26–28 Because recipients and families have experienced such stress and because the drugs on which their lives depend have multiple, occasionally life-threatening, side effects,17, 21, 30 recipients’ own assessments of transplant results and the distress caused by continuing symptoms are needed to balance the observations of transplant groups.

Evans’ results from the National Heart Transplantation Study indicate that, “On every quality of life indicator, except functional impairment, heart transplant recipients have a lower overall quality of life than kidney transplant recipients. . . . With the exception of life satisfaction, however, heart transplant recipients reported a higher quality of life than dialysis patients.”20 In a study conducted by Lough et al.,31 89% of the 75 recipients responding rated their quality of life as good to excellent. Eighty-two percent were satisfied to very satisfied with that quality. A number of life changes were reported with a surprising proportion of these in a positive direction. Relationships with family members, work associates, and friends were described as significantly improved. Similar positive changes were reported in recipients’ feelings about themselves, the future, and their senses of accomplishment and independence. Significant negative changes included recipients’ financial status and physical appearance.

The Lough group also asked respondents to rate the frequency with which they experienced common side effects of immunosuppressant drugs and to indicate the level of distress experienced because of each symptom. Although quality of life and life satisfaction were negatively associated with the number of symptoms and the distress caused, “the symptoms that occurred
most frequently were not. . .[the] most upsetting.”
For both azathioprine- and cyclosporine-treated recipients, impotence and decreased interest in sex caused the greatest personal distress.

**Epilogue.** The longest survivor in the Stanford transplant series received his heart on January 3, 1970. Others are alive and well five to fifteen years after transplant. Realistically, none had an “easy” course. Neither they nor their families escaped the anxiety and pain of the transplant process, and all have lost friends who were also recipients through the intervening years. Some have themselves experienced life-threatening complications. Yet, from a number of perspectives, the worry, fear, and upheaval of transplantation were worth it, not only for the recipients and families, but also for the physicians and hospital staff who worked so hard to achieve patient survival and independence. Statistics on “rehabilitation” mask the self-esteem and daily pleasure felt by real people whose primary identity is now corporate attorney, school principal, or PTA president. Recipients accomplish goals that were important to them and set new ones.

“Remember how I wanted to see my youngest daughter graduate from high school? Well, lately I’ve been thinking a lot about her college graduation.”

Nurses see recipients they once taught encouraging new patients or returning for annual studies supremely confident of the drugs that at first overwhelmed them.

“Sending a [knowledgeable] patient home...is a major [nursing] accomplishment.”

Physicians have namesakes scattered about the country, and the careers of those who were “chief transplant resident” are followed with pride by recipients whose lives are interwoven with theirs. When death occurs years after the transplant, the family is often as supportive and protective of the original transplant staff as the staff is of them. “Please don’t ever worry that the transplant might not have been worth it to us. Our extra years together were special.”

I thank Susan Randlett for her assistance in the preparation of this manuscript.

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CIRCULATION
Cardiac transplantation: a psychological perspective.
L K Christopherson

Circulation. 1987;75:57-62
doi: 10.1161/01.CIR.75.1.57
Circulation is published by the American Heart Association, 7272 Greenville Avenue, Dallas, TX 75231
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Print ISSN: 0009-7322. Online ISSN: 1524-4539

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the World Wide Web at:
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