

# QUALITY OF LIFE

## *Organ Transplantation and Artificial Organs*

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This article describes issues that are clinically significant when assessing quality of life of patients whose organ disease can be treated only through transplantation or reliance upon an artificial organ. Emphasis is placed on stresses that affect the family as well as the immediate patient, because, over time, these are inextricably interwoven. The transplant recipient who experiences a “good” medical outcome may perceive that he has little to live for if his family is severely disrupted or broken apart by the strain of the illness. The family of a patient who dies after unremitting complications while being sustained by an artificial organ may experience both relief at the lifting of an unmanageable burden, and continuing guilt that they were unable to provide unconditional love and support to a dying family member.

Efforts to define or quantify “quality of life” precisely are beyond the scope of this article. Rather, it is based on a review of recent literature and the author’s work with patients undergoing transplantation and/or artificial organ support, and with members of their families. The perspective is that of perceived satisfaction, the ability to return to pre-morbid activities, and the patients’ and families’ personal descriptions of the impact of the illness and medical intervention on their lives.

### ONSET OF ILLNESS

Although quality of life discussions often focus on the outcome for the patient of medical intervention, changes which have a marked impact on quality of life begin with the discovery of life-threatening illness. Common reactions for both patient and close family members include experiencing the first four stages of reaction to terminal illness as described by Kübler-Ross: denial and isolation, anger, bargaining, and depression (16).

If the illness is one for which transplantation and/or a mechanical organ substitute is available, emotional progression toward the fifth stage, acceptance of death, is attenuated. The primary focus of the patient's and family's attention, energy, problem-solving efforts, and finances is placed on obtaining access to the needed organ or machine. Efforts are begun to convince themselves and relevant "gatekeepers" that the patient's chances for survival are unusually favorable because of desirable family characteristics or the patient's "will to live."

As these steps are taken, changes in the behavior of family members, and thereby the quality of patient and family life, almost inevitably occur. Families with open communication prior to the illness may find themselves comfortably sharing rapidly changing feelings of anger, depression, and denial while simultaneously organizing their fight for the patient's survival (22). Other families, whose communication has been less open or whose feelings are not as synchronous, may find themselves moving apart in an effort to alleviate pain and to protect certain members, often the very young or very old, from the disruption that has occurred.

If a relative is sought as an organ donor (e.g., a related kidney transplant), extended family relationships can undergo rapid change and increased tension. If the transplant is cadaver based but involves a move of unknown duration from the home community, as is often required with heart, liver, or heart-lung transplantation, extended family members may find themselves uncomfortably pressed to provide financial assistance or child care. The patient's family may find itself in the position of discomforted supplicant.

Although a few families respond to life-threatening illness by isolating the patient, the more common response is to focus additional attention and caring on the gravely ill family member. Despite the potential benefits to the patient, the risks to the family as a whole are considerable. When the patient is a child, siblings may experience marked difficulty in school and in relationships with peers because of the decrease in available parental attention. Spouses may find the pressure to "be strong" from family, friends, and health care professionals more than they ultimately can carry. Most medical centers with large transplantation or artificial organ programs have had at least one experience in which the patient was hospitalized "upstairs" and the spouse hospitalized "downstairs."

Financial pressures and a change in family financial status usually begin during the illness phase. If the patient's employment income provides for the family, that income may diminish or cease. Even if the patient is not a family breadwinner, the discretionary income of the family—and some that was not previously perceived as discretionary—is required to pay for medical care, drugs, and travel and living expenses associated with obtaining treatment. Community fund raising is often necessary to meet the costs of transplantation or artificial organ support when third party assistance is not available or sufficient. Even this has problems as well as benefits in terms of the patient's and family's sense of independence, privacy, and self-respect. When funds are controlled by family members, they may feel guilt and embarrassment spending money known to have been donated by friends. When funds are controlled by outside organizers or a bank officer, the patient and family members may have the sense of reporting to an external "board of directors" about relatively intimate details of their lives.

## CHARACTERISTICS OF THE TRANSPLANTATION/ ARTIFICIAL ORGAN PHASE

For most patients and families the pre-eminent characteristic of the transplantation/artificial organ implementation phase is uncertainty. Uncertainty of outcome predominates, particularly when failure of the graft is apt to mean death (4). Uncertainty about morbidity, however, carries almost equal weight. Patients and families fear, for example, that use of an artificial heart either temporarily or permanently will result in cerebrovascular impairment, or that use of immunosuppressant medication will pave the way for life-threatening infection or carcinoma (10,17).

Loss of a transplanted kidney, although the recipient is protected by the availability of dialysis, can be physically and emotionally debilitating. If the non-functioning kidney was donated by a family member, both donor and recipient are subject to guilt, anger, and an acute sense of loss. If the non-functioning kidney came from a cadaver, the patient may feel that his months or years of being "good" on dialysis were all in vain. The patient's suppressed anger about life on dialysis may become conscious with hope that the graft will succeed. The patient may find it much more difficult to keep these feelings under control when he returns to the machine.

The process of change in the roles played by various family members, begun during the illness phase, is likely to continue and to accelerate during the period of transplantation or the patient's initial dependence upon the artificial organ. If the patient is an adult, primary responsibility for the management of family finances and for parenting, for example, almost inevitably falls to the non-ill spouse. Although the result can be an increase in distress for an already pressured spouse, it can also lead to a marked increase in self-esteem and the desire to maintain authority. "John always took responsibility for disciplining the children and for making the decisions about family finances. Now that I have had my chance, he's never getting full control again."

When the patient is a child, siblings often experience more than simply the loss of what they consider their "fair share" of parental attention. The occasional wish that the sibling would die is accompanied by guilt and potentially the belief that the child has magically caused death to occur if death is the outcome. The child may also, realistically, assess that the life-threatening illness of an older sibling presages his own illness to come. One troubled 13 year old, for example, watched as his eighteen-year-old brother died three months following cardiac replacement for familial cardiomyopathy. Recuperating in the room next to his brother was the 12-year-old sibling of a 15-year-old boy who had been transplanted less than three years before.

For most patients undergoing organ replacement or substitution, the medical intervention occurs some distance from the home community. The result, for both patient and accompanying family members, is a loss of day-to-day friendship, supports, and community activities that are usually available to them. In the absence of such supports, the patient and family members can feel not only more emotionally vulnerable but also less well defined and regarded as individual human beings. As one patient described it, "At home, I am president of the Chamber of Commerce, owner of my own business, and a pretty important man around town. Here the nurses make up my daily schedule like they were training a puppy."

The limited availability of donor organs, the methods by which organs are allocated, and the detailed protocol by which subjects for temporary or permanent mechanical circulatory support devices are selected all may be experienced as unfeeling and capricious. This is compounded by the fact that public fund-raising appeals and even appeals for scarce vital organs may depend as much on the photogenic appearance, media sophistication, and "news-worthiness" of the patient and family as it does on documented need. Ironically, the widespread availability of hemodialysis and its funding through federal entitlement also may pose difficulties for some patients and members of their families. The decision not to pursue cardiac transplantation or replacement with a permanent mechanical device is generally well accepted either when a series of physicians determines that it has a negligible chance of success or when the patient decides that the intervention is not one to which he personally would consent. The ability of either physician or patient to decide against initiating hemodialysis, however, even in the face of extensive co-morbidity, is more constrained. So also is the ability of the patient, family, or physician to stop dialysis on the basis of quality of life once treatment has been started.

## WHEN SURVIVAL OCCURS

Quality of life, when survival occurs, is exceptionally difficult to measure. The only parameters with inarguable reliability and validity are 1) alive versus dead, and if alive, 2) hospitalized or not hospitalized. Regrettably, despite their ease of measurement, these parameters say little about other issues of importance to individual patients and their families.

During the first few years of trials of a new procedure or mechanical organ substitute, survival is often measured in months rather than years. Patients equate reasonable quality of life with the capacity to be present at activities and events which would otherwise be lost to them through death. Among the accomplishments that importantly defined quality of life for early cardiac transplant survivors were watching a son quarterback his alma mater's homecoming game, living long enough so that a two-year-old daughter would remember him after he died, holding a first grandchild, and watching the episode of Hawaii Five-O of which the recipient was a co-author. Parallels to these goals can be seen today in the motivation of patients who are willing to undergo cardiac replacement with a permanent artificial heart. To the extent that these goals can be achieved, even if survival is brief, the patient and family may judge that the intervention was successful and that the stresses and problems associated with it were a price that they chose to accept.

As survival lengthens, however, additional factors become important to the patient's and family's assessment of quality of life. While the weight of any single factor depends upon the patient's age, family constellation, and the value which was previously given to activities ranging from competitive employment to community service, there are a number of characteristics and activities which appear significant in most patients' assessment of quality of life.

The first factor is that of freedom from fear of sudden death or failure of the graft or machine leading intractably to death. Kidney transplant recipients, for example, know that the return to hemodialysis provides a measure of protection

for them. Liver and heart transplant recipients are trained to recognize the early stages of rejection and to cooperate with physicians in appropriate diagnosis and treatment. Most have experienced one or more rejection episodes that were amenable to therapy. Most are also acquainted with one or more patients who have undergone successful retransplantation of the vital organ.

The ability to achieve reasonable freedom from fear for recipients of a permanent artificial heart is a significant concern for medical and allied health professionals working with or preparing to work with these patients. If unanticipated death from failure of the machine or from blood clots travelling to the brain becomes a major cause of death of patients who are otherwise doing well, then quality of life will be compromised by chronic, anticipatory fear.

The capacity to return to a normal family life and to participate in family activities that previously have been meaningful is a second factor important to most recipients. Parenting includes the ability to love and to listen as well as the ability to participate in at least moderate physical activity with the children. For recipients who have not yet reached adulthood, a return to normal family activities means the ability to play, to share, and even to fight with parents and siblings who feel that the family constellation is happier and more complete with the patient still there (22).

Most follow-up studies of dialysis patients and survivors of transplant procedures focus on the ability of the patient to return to school, to competitive employment, or to full-time household management. This has the advantage both of providing relatively objective information about the patient's activities and of reflecting characteristics of rehabilitation likely to be valued by the patient, family members, and the community. Such studies also provide an indirect measure of the patient's physical, intellectual, and emotional competence. If significant emotional, cognitive, or physical disabilities are present, these activities likely would be restricted or precluded.

## Cardiac Transplantation

Rehabilitation for cardiac transplant recipients, reported primarily by the Stanford University Transplant Group and through a study commissioned by the British Department of Health and Social Security, clearly has been favorable. A 1985 analysis of transplant programs at Harefield and Papworth Hospitals in Great Britain indicated that 19 of 38 recipients interviewed had returned to work, 4 were full-time wives and mothers, and several others were pursuing volunteer activities and avocational interests. Unemployment was perceived to be a function of the economy and not of physical disability. Subjective descriptions of quality of life were consistently positive.

A 1976 study of 56 Stanford cardiac recipients classified 91% of the patients as successfully rehabilitated (6). Subsequent reports describing both the cohort of recipients under age 30 (24) and all recipients (23) indicate similar results. Of particular interest is the fact that in the study of cardiac transplant recipients under age 30, "64 percent of the patients considered their health to be better or about the same as for most people their own age (24)." While the accuracy of this belief might be debated, a recent study of end-stage renal disease patients

also found that patients reported a higher degree of subjective satisfaction than would be predicted by the objective data (9).

The rehabilitation and quality of life for these transplant survivors is encouraging, but it remains to be seen whether similar results will be achieved by the large number of centers in which cardiac transplant programs are now underway. "It has been possible to rehabilitate the majority of Stanford's surviving cardiac transplant patients, in part because of the stringent patient selection criteria which Stanford has, and in part because Stanford works intensely with a small number of patients. The fact that recipients are very carefully selected and are closely tended by Stanford staff before, during, and after surgery appears crucial for the success of the Stanford program" (18).

## Liver Transplantation

Data concerning rehabilitation and quality of life following liver transplantation is more limited both because of the youth of many of the recipients and because of the relatively poor outlook for extended survival until recent years. "Prior to 1980, survival at one year averaged 30 percent with an excellent long term outlook for those who had normal liver function at one year after transplantation" (13). Survival rates for patients with non-neoplastic disease who were transplanted after January 1, 1980, show improvement over these earlier results (25).

Studies of liver transplant survivors indicate that virtually all are likely to experience psychiatric disturbance during the perioperative period, but that the degree and nature of the disturbance diminishes markedly as survival becomes established (15;27). A study of 10 patients who had functioning grafts for an average of three years demonstrated almost no substantial difference in psychiatric status and social functioning from a control group of patients with non-life threatening, chronic disease. "However, when contrasted with normative population values, the transplant patients presented a profile of moderate anxiety, somatic distress and concern, frustration, depression, worry, and social withdrawal" (27).

A recent, extensive study of 540 liver transplants performed at four centers in the United States and Europe attempted to assess quality of life from the data gathered. Information regarding 184 patients surviving more than four months from centers in the Netherlands, West Germany, and England, indicated that "179 were listed in good condition (fully rehabilitated), while only three were listed in fair condition (able to care for self), and two in poor condition (needs care). A recent survey of transplant recipients [at the fourth center, the University of Pittsburgh] indicated that greater than 80 percent of patients surviving longer than one year had resumed their former occupation or activities" (25).

The intensity of the effort required to obtain these rehabilitation statistics, however, may be both understated and a significant caution for other centers that develop liver transplant programs. The University of Pittsburgh group, describing liver transplantation in 47 children, writes as follows: "The price of liver transplantation is a high one for most children. . . . Children and families are stressed constantly as to some extent is the medical staff. . . . An intensive team effort is absolutely necessary for success, a team that includes nursing, social services, psychiatry, psychology, occupational and play therapy, and others who are aware of the special problems and needs of patients who have received transplants (13)."



## Renal Transplantation and Hemodialysis

Follow-up studies of patients receiving kidney transplants also reveal positive results both in terms of rehabilitation and in the patients' evaluations of their quality of life. In a study of 855 patients with end-stage renal disease from 11 dialysis and transplantation centers nationwide, Evans and his colleagues, "found that 79.1 percent of the transplant recipients were able to function at nearly normal levels" and that 74.1% of the transplant recipients (unadjusted for case mix) considered themselves able to work (9). Flechner and colleagues reporting on 45 kidney transplant recipients who had received grafts at the Cleveland Clinic 10 or more years prior to the study, indicated that 44 recipients were competitively employed, engaging in full-time housework, or studying in a degree program (11). The source of the graft, cadaver or living related donor, did not make a difference in the functional capacity of the recipients in either of the studies (8;11).

The likelihood of rehabilitation and the subjective perception that quality of life is satisfying is lower for end-stage renal disease patients undergoing hemodialysis or continuous ambulatory peritoneal dialysis (CAPD) than it is for transplant recipients. The percent of patients who perceive themselves able to work, described by Evans and colleagues, drops from 74.1% for transplant recipients to 69.3% for home dialyzers, 37.2% for those dialyzed in center, and 24.7% of those receiving CAPD (9). Data presented by Simmons and colleagues describing male end-stage renal disease patients surveyed in 1983–84 indicate that 78% of the transplant recipients, 54% of those receiving CAPD, and 32% of those on hemodialysis are working or in school full- or part-time (26).

In both studies the subjective indicators of quality of life and the patient's descriptions of their emotional well-being are significantly higher for transplant recipients than for those on dialysis. Although the data is not directly comparable, patients on home dialysis appear to report a significantly better sense of well-being and satisfaction than those whose dialysis is center based. Patients undergoing CAPD, despite the incidence of peritonitis, often report preferring it to hemodialysis (26).

The preference for transplantation over dialysis, diminution in physical and mental capacity, and the rigors of dialysis itself may occasionally lead a patient or significant family members to terminate treatment despite the recognition that death will result. Several articles during the early 1970s described the incidence of suicide and suicidal behavior in chronic dialysis patients (1;14;19). One article described the authors' clinical observations that kidney transplant recipients who had experienced a variety of complications and stresses began actively "to explore their options, including death, in the event the graft failed" (5).

Evan's recent study of ESRD patients appears to indicate that the subjective indicators of quality of life for dialysis and CAPD patients are higher than would be predicted by the objective measure of quality of life. "The evidence remains clear that, with the exception of transplant recipients, patients with end-stage renal disease have a poorer objective quality of life. In short, patients on dialysis are clearly not functioning like people who are well, despite the fact that they are enjoying life" (9).

Necessarily, data that summarizes either objective or subjective measures of quality of life diminishes the attention focused on patients whose perceptions and

experiences are appreciably worse (or better) than the average. A recent study of cessation of chronic dialysis in 165 patients found detailed descriptions of the decision to stop treatment in 132 of their medical records. Half of the patients were competent, and half were not. "Of the 66 competent patients, 58 made the decision to stop [dialysis on their own]" (21). Discussion of cessation of treatment for the 66 patients "who were incompetent because of dementia, strokes, or coma" (21) was initiated by physicians in 73.4% of the cases, and by families in 26.6%. Court action either during or following the stopping of dialysis occurred in only one instance. "Dialysis was discontinued in 155 (9 percent) of the 1,766 patients being treated" between the period of January 1, 1966, and July 1, 1984 (21).

### Artificial Heart Implantation

The first human implantation of a permanent total artificial heart took place at the University of Utah in December 1982. The recipient, Dr. Barney Clark, survived for 112 days, but his course was plagued by medical (7;29) and psychiatric (2;12) complications. Four additional patients subsequently received permanent total artificial hearts, three at Humana Hospital Audobon in Louisville, Kentucky, and one at Karolinska Hospital in Stockholm, Sweden. Of the four additional recipients, only the Swede, who is now deceased, was able to function independently of hospital care for any length of time. By August 1986, all three had died; one had suffered a series of crippling strokes and all were hospitalized or hospital dependent. A number of other patients have had ventricular assist devices or "artificial hearts" used as interim bridges to cardiac transplantation.

Results to date for recipients of the permanent total artificial heart have not been good. None of the five recipients, with the possible exception of the Swedish businessman, has been able even briefly to return to his usual vocational or avocational activities. William Schroeder, a Louisville recipient, survived until, and beyond, his son's wedding but was not medically stable enough to attend; he died after 22 months. Of the two remaining recipients, one died after ten days, and the second, hospitalized continuously after the implant, died after 16 months.

The long term outlook for the use of the total artificial heart is not known, but serious quality of life problems are raised by the generation of mechanical assist devices currently in use. To the extent that the power source is external, connected to the patient by pneumatic tubes and too bulky to be moved and transported readily by the patient, the patient's freedom and quality of life are severely compromised even if problems of clotting can be overcome. The 1985 report of the Working Group on Mechanical Circulatory Support of the National Heart, Lung, and Blood Institute, approved by the NHLBI Advisory Council, recommended that future research should focus upon a fully implantable, long term artificial heart. However, it emphasized that study of quality of life issues for the patient and family should be as much a requisite for research funding as technological and clinical expertise (20).

A recent article in *Time Magazine* (28) was entitled: "Implants: A Family Affair." Although naive in its apparent belief that the families of artificial heart recipients are suffering more or differently from the families of other patients who were early transplant or artificial organ recipients, its underlying theme was ac-



curate. "The families . . . are, in every sense, fellow participants in a grueling human experiment." Problems of quality of life for total artificial heart recipients surround their families as well.

## SUMMARY

Changes in quality of life for patients who require transplantation or permanent artificial organ support begin with the onset of serious organ dysfunction. These changes, which initially are almost universally negative, greatly affect close family members as well as the patient. To the extent that alternate therapies are available, transplantation appears preferable to chronic artificial organ support in allowing the patient to return to work, to school, or to similar self-selected activities.

There is some evidence that transplant and artificial organ patients may describe their subjective well-being more positively than would be anticipated from objective data. There is also evidence, at least for hemodialysis patients, that this satisfaction is time-limited. The right to choose death over life dependent on a machine is being exercised by some alert patients as well as by family members and attending physicians when the patient is not competent.

Little data is available regarding the long-range impact of transplantation or artificial organ support on members of the patients' families, but in the author's experience one characteristic predominates. To the extent that the life-extending therapy can be forgotten, or is non-intrusive, for days or weeks at a time, as can be the case with transplantation, family functioning returns to normal. The adjustments needed to cope successfully with the stresses of the acute phase are completed. To the extent that reminders and uncertainties of the therapy are chronically present, family interaction continues to center upon (or is designed to avoid) the patient. The family's resilience and capacity to maintain its integrity diminish with each new stressful event.

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