

Quality of Life of Pancreatic Transplant Recipients

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OBJECTIVE— To comprehensively assess and compare pancreas/kidney transplant recipients' quality of life.

RESEARCH DESIGN AND METHODS— This quasi-experimental comparative study of 31 successful and 13 failed pancreas transplant recipients collected data from persons who had received pancreas and kidney transplants ≥ 6 mo prior at a university tertiary care center. Physical and social function, symptoms, mental state, and sense of well-being of the recipients were assessed.

RESULTS— Groups did not differ significantly regarding age, gender, marital status, onset or length of diabetes, comorbidity, type of prior dialysis, current kidney function, length of time since transplant, physical activity, symptom burden, emotional state, feelings of well-being, and present quality of life and health. A significant time by group interaction occurred for quality of life ($P = 0.0013$) and health ($P = 0.0001$). The successful group indicated that both quality of life and health were significantly better than in the past, and continued improvement was expected. The unsuccessful group did not have this perception. Members of the failed group were significantly more satisfied with their social support. The unsuccessful group's major concerns related to diabetes, not immunosuppression.

CONCLUSIONS— Recipients of successful pancreas transplants perceived their improvement in health and quality of life to be significantly greater than the unsuccessful recipients.

Treatment options for type I diabetes historically have revolved around a blending of intensive insulin therapy, dietary management, exercise, and management of complications. Pancreatic transplantation is now also becoming a viable treatment option (1). According to the International Pancreas Transplant Registry (2), >2500 such procedures have been performed world-

wide with 1-yr graft survival rates approaching 70% and patient survival rates >90%.

Survival is not the only criterion in the evaluation of treatment efficacy. The quality of treated individuals' social existence is equally important when assessing treatment outcomes (3). Measurement of quality of life is a complex process that involves objective quantification of individuals' functional ability in tandem with their subjective quantification of perceptions and feelings. Spitzer (3) suggested that any assessment of quality of life should include five areas: physical function, social function, burden of symptoms, emotional or mental state, and sense of well-being.

In a longitudinal study of successful transplant recipients (1), patients noted improvement in their secondary complications and were satisfied with the procedure. Two other studies found that the pancreas/renal transplant recipients rated their quality of life higher than their renal recipient counterparts (4,5). A study of 131 subjects found that those with functioning pancreas grafts had significantly more positive assessments of quality of life, health, and activities of daily living than did subjects with non-functioning pancreas grafts (6). In a second multidimensional study, significant differences did not occur in the dimensions measured (7).

The purpose of this exploratory descriptive study was to comprehensively assess the quality of life of successful and unsuccessful pancreas transplant recipients. The specific aims were as follows: 1) to identify the physical function, social function, burden of symptoms, emotional/mental state, and sense of well-being of transplant recipients who received both kidney and pancreas grafts, and 2) to compare the quality of life of transplant recipients who have a functioning pancreas and kidney grafts with recipients who have a functioning kidney, but failed pancreas graft, who have resumed insulin therapy.

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HI.OC, HEALTH LOCUS OF CONTROL; MAACL, MULTIPLE AFFECT ADJECTIVE CHECKLIST; ANOVA, ANALYSIS OF VARIANCE; TYPE I DIABETES, INSULIN-DEPENDENT DIABETES MELLITUS.

RESEARCH DESIGN AND METHODS

All patients who received pancreas transplants at the University of Iowa ≥ 6 mo prior to data collection and between January 1985 and December 1989 were reviewed for suitability for this study. Selection criteria included adult patients with type I diabetes who were sighted, had received a previous or simultaneous successful kidney transplant (current creatinine < 3.0 mg/dl), were not hospitalized with an acute illness at the time of data collection, and did not have other major illnesses. A review of the 63 patients still living yielded 46 potential subjects.

Based on Spitzer's (3) suggested categorizations, 11 questionnaires were used to assess five quality of life dimensions: physical function, social function, burden of symptoms, emotional/mental state, and sense of well-being. All questionnaires have been used previously with transplant and/or dialysis populations.

The physical ability of each patient was rated by the transplant nursing staff using the Karnofsky Index (8). This index is a measure of overall functioning related to the ability to perform activities of daily living. Scores ranged from 0 (moribund) to 100 (normal activity). The subject's level of fatigue was assessed using the Pearson and Byar's Subjective Fatigue Checklist (9). This 10-item list asks subjects to compare how they currently feel with statements related to levels of energy and fatigue. Information also was gathered regarding duration of diabetes, dialysis experience, and type and duration of renal and pancreas transplants.

Social function was assessed in part by Myer's Resources and Social Support Questionnaire (10). Subjects ranked the importance of and their level of satisfaction with five types of social support: receiving advice, praise/criticism, practical help, emotional support, and socializing with friends. Social function also was measured through open-ended questions that asked subjects to describe their past and present employment. The

following information was obtained to supplement the social description of the subjects: age, gender, level of education, marital status, and number of children.

The burden of symptoms was assessed using Parfrey's Physical Symptom Scale (11). Subjects were asked to indicate the presence and severity of 11 symptoms common among the renal failure population on a 5-point Likert scale that ranged from none to extremely bad. The list included tiredness, headaches, cramps, itchiness, dyspnea, angina, lack of sleep, joint pain, muscle weakness, vomiting/nausea, and abdominal pain. They also were asked to add symptoms necessary to fully describe their physical symptom burden. Additional open-ended questions asked about the presence of treatment problems, such as medication side effects, and concerns.

The emotional/mental state of subjects was assessed by measuring happiness, energy, locus of control, depression, anxiety, and hostility. Happiness and energy were measured by Gill's 50-item adjective checklist (12). The Multidimensional HLOC was used to determine whether the subject ascribes control over personal health outcomes to chance, powerful others, or internal causes (13). Depression was assessed using the Beck Depression Inventory (14) and the MAACL by Zuckerman and Lubin (15). The multiple checklist assessed the negative affects of anxiety, hostility, and depression.

The fifth dimension of quality of life, sense of well-being, was assessed by measuring subjects' self-esteem, perceptions of well-being, and perceptions of quality of life and health. Self-esteem was measured by Simmon's Self-Esteem Scale (16), a 10-item scale used previously with chronically ill patients and the renal transplant population. Subjects' sense of well-being was further measured by Campbell's Index of Psychological Affect and Index of Life Satisfaction. These two scores are combined to produce an overall assessment, the Index of Well-Being (17). Lastly, Cantril's Self-

Anchoring Striving Scale (18) allowed the subjects to identify their perception of past, present, and future quality of life and health. Two additional open-ended questions asked subjects to identify factors that influence the quality of their life and their satisfaction with the pancreas transplant.

The 11 questionnaires, incorporated into a comprehensive packet, were mailed to the subjects.

Statistical method

The groups were compared using the Student's *t* test to analyze the continuous variables, except for Cantril's Self-Anchoring Striving Scale. Results from this index were analyzed by repeated measure (past, present, and future) ANOVA. The χ^2 test of independence was used to analyze data for categorical variables. The level of 0.05 was established for significance.

RESULTS—Forty-four (96%) of the invited transplant recipients completed and returned the questionnaires. The two refusals were from the failed group. The 31 successful transplant recipients did not differ significantly from the 13 failed recipients regarding age, gender, marital status, and education level (Table 1). In addition, the groups did not differ significantly regarding number of children, age or length since onset of diabetes, preoperative incidence of retinopathy and neuropathy, type of transplant (kidney and pancreas), type of prior dialysis, or length of time since transplant (Table 2). Almost all of the pancreas failures occurred within the first week after surgery—the result of thrombosis. All patients were on immunosuppressive therapy, with most on triple immunosuppression (imuran, prednisone, and cyclosporine).

Group comparisons

Physical function. The two groups did not differ significantly regarding levels of fatigue and activity (Table 3). Almost all individuals in both groups rated them-

Table 1—Frequency distribution for demographic variables for pancreas transplant recipients

	SUCCESSFUL TRANSPLANT (N = 31) F (%)	FAILED TRANSPLANT (N = 13) F (%)
SEX: MALE/FEMALE (% MALE)	18/13 (58.1)	7/6 (53.8)
MARITAL STATUS		
MARRIED	18 (58.1)	7 (53.8)
SINGLE	11 (35.5)	3 (23.1)
DIVORCED	2 (6.4)	3 (23.1)
EDUCATION LEVEL		
HIGH SCHOOL OR LESS	10 (32.3)	4 (30.8)
SOME COLLEGE	10 (32.3)	4 (30.8)
COLLEGE/ADVANCED DEGREE	11 (35.5)	5 (38.4)
PREOPERATIVE COMPLICATIONS		
RETINOPATHY	26 (83.8)	12 (92.3)
NEUROPATHY	20 (64.5)	8 (61.5)
TYPE PANCREAS TRANSPLANT		
SEQUENTIAL	6 (19.4)	7 (53.8)
SIMULTANEOUS	25 (80.6)	6 (46.2)
DIALYSIS BEFORE TRANSPLANT	19 (61.3)	11 (84.6)
TIME SINCE PANCREAS TRANSPLANT		
0–1 YR	11 (35.5)	1 (07.7)
2–3 YR	7 (22.6)	7 (53.8)
4–6 YR	13 (41.9)	5 (38.5)

selves as able to perform normal physical activity at least part of the time. The mean Karnofsky score of the subjects was at a level of almost normal activity. The mean score on the Pearson and Byars Fatigue Scale for the subjects indicated that they felt somewhat fresh.

Social function. Both groups perceived all aspects of social support to be important. The failed group was significantly more satisfied with the support they received (Table 4). The ability to work before transplant was similar for the two groups. Fifty-eight percent of the successful group and 46% of the failed group were employed. Generally, subjects maintained their previous employment pattern after surgery.

Burden of symptoms. Physical symptoms were experienced equally by both groups. The average number of symptoms experienced was 4.6 (range 1–12). The four most commonly occurring symptoms experienced were tiredness (90%), muscle weakness (64%), lack of sleep (59%), and joint pain (50%). Of

the successful group, ~50% had problems related to the side effects of the immunosuppressants. The predominant problem identified by the failed group related to the complications of diabetes, even though all patients were obligated to immunosuppressant therapy.

Emotional/mental state. No significant differences were found between the groups in level of happiness, energy, lo-

cus of control, depression, anxiety, or hostility. Subjects perceived that they did have energy and were happy, but not at high levels. Depression scores were below the level indicative of clinical depression, and anxiety and hostility means were within the normal range. The subjects' mean HLOC subscores were higher than healthy norm groups (13) regarding their perceptions of the impact of chance and powerful others on their lives.

Sense of well-being. The groups did not differ significantly regarding self-esteem, well-being, and present quality of life and health. The mean self-esteem score for all subjects was at a level indicative of moderate self-esteem. The mean score for Campbell's Well-Being Index for all subjects was slightly lower than the mean of a national adult reference group ($n = 2164$) (17).

A significant time by group interaction was present for quality of life ($P = 0.0003$) and for health ($P = 0.0001$) when repeated measure ANOVA was done. Post hoc comparisons of the two groups, at each time, revealed that the groups differed significantly regarding their perception of prior quality of life. The successful group perceived their prior quality of life to be much lower than did the unsuccessful recipients. Perceptions regarding expected future quality exhibited a trend for more positive ratings in the successful group.

Table 2—Demographic variables for pancreas transplant recipients

	SUCCESSFUL TRANSPLANT (N = 31)	FAILED TRANSPLANT (N = 13)
AGE (YR)	37.0 ± 5.9	39.9 ± 3.9
NUMBER OF CHILDREN	1.9 ± 1.5	1.2 ± 1.0
DIABETES HISTORY (YR)		
ONSET AGE	9.9 ± 5.2	9.2 ± 5.8
LENGTH SINCE ONSET	27.1 ± 6.4	30.7 ± 4.9
LENGTH SINCE TRANSPLANT (YR)		
RENAL	3.2 ± 2.4	4.1 ± 2.5
PANCREAS	2.9 ± 1.8	3.0 ± 1.3

Values are means ± SD.

Table 3—Continuous quality of life variables for pancreas transplant recipients

	SUCCESSFUL TRANSPLANT (N = 31)	FAILED TRANSPLANT (N = 13)
PHYSICAL FUNCTION		
KARNOFSKY (ACTIVITY) SCORE	88.7 ± 6.9	88.5 ± 9.7
LEVEL OF FATIGUE	18.2 ± 3.4	18.4 ± 3.7
BURDEN OF SYMPTOMS		
NUMBER OF SYMPTOMS	4.6 ± 2.8	4.5 ± 1.8
INTENSITY OF SYMPTOMS	4.9 ± 2.2	4.3 ± 1.2
EMOTIONAL/MENTAL STATES		
ENERGY	4.5 ± 8.1	7.2 ± 5.8
HAPPINESS	10.7 ± 6.7	10.1 ± 6.4
BECK'S DEPRESSION INVENTORY	8.1 ± 5.1	9.6 ± 8.5
DEPRESSION MAACL	11.2 ± 5.5	12.6 ± 7.1
HOSTILITY MAACL	6.5 ± 3.6	5.9 ± 3.7
ANXIETY MAACL	6.5 ± 4.2	5.3 ± 4.0
HLOC		
INTERNAL	25.1 ± 5.1	26.8 ± 4.3
POWERFUL OTHER	22.7 ± 3.9	20.5 ± 4.0
CHANCE	17.8 ± 4.3	15.3 ± 4.9
SENSE OF WELL-BEING		
SELF-ESTEEM	31.4 ± 4.0	30.8 ± 3.1
WELL-BEING INDEX	10.7 ± 2.4	9.9 ± 3.4
GENERAL AFFECT	41.9 ± 9.0	38.8 ± 12.3
LIFE SATISFACTION	5.0 ± 1.5	4.6 ± 1.8
LIFE		
PAST	3.1 ± 2.1	5.0 ± 2.9
PRESENT	7.4 ± 1.6	6.7 ± 1.5
FUTURE	8.2 ± 1.4	7.0 ± 1.8
HEALTH		
PAST	2.5 ± 1.8	5.2 ± 2.8
PRESENT	7.5 ± 1.5	6.2 ± 1.6
FUTURE	8.1 ± 1.3	6.0 ± 2.1

Values are means ± SD.

Post hoc comparisons of the health means for each group at the different time periods revealed differences only in the successful group. They perceived their past health to be significantly worse than their present and future health quality. Comparisons between the two groups at the different time periods revealed significant differences between the groups' perceived health quality in both the past and future time periods.

CONCLUSIONS— It was anticipated that the selection criteria for pancreas transplantation would limit the range of difference present in the recipients prior

to surgery. However, it was surprising to find how similar the two groups were after surgery, whether the transplant was a success or a failure.

This cross-sectional study, which used a cohort design, included the entire population during a specific time period. The small sample size may account for the lack of significance that occurred with the various measures. Power calculations for this size group, using a medium effect, indicate an overall power level ranging from 0.4 to 0.5 (19). The multiple comparisons, of course, may have resulted in significance occurring by chance.

Studies of individuals with chronic illness have found that they rated their quality of life and health status as similar to norm groups of healthy persons. This finding suggests that the quality of life of persons with chronic illnesses should be viewed according to their standards and not with those of their care providers nor of healthy persons. Patients' perception of their health is a key factor in their adjustment to chronic illness (20). The difference in ratings over time of the successful group may indicate the change these patients perceive accruing from transplant. Although the reliability and validity of patients' retrospective ratings of health may be questioned regarding true past status, this is not the pertinent aspect of the rating. What is pertinent is how subjects currently view their past health. Such a rating in tandem with their future expectations is indicative of what subjects perceive as their gain. The successful group indicated that both health and life are significantly better than in the past, and continued improvement is expected. The unsuccessful group did not have this perception. Prospective long-term follow-up studies involving a matched control group of individuals with diabetes who do not desire a pancreas transplant is needed to identify more clearly the positive and negative impact of pancreas transplantation on quality of life, particularly in those who have a graft failure.

All of the patients in the study were made dialysis-free by the kidney transplant and were obligated to immunosuppression. The central questions for such a population are, does adding a pancreas enhance the quality of life over and above that of performing only a kidney transplant, and is it worth the surgical risk? The unsuccessful group, who identified that their major concerns related to diabetes, raises questions about how these patients view these two treatment regimes. In a study by Zehrer and Gross (6), >90% of subjects reported that the immunosuppressive regime was easier to manage and less demanding on

Table 4—Frequency distribution for categorical quality of life variables for pancreas transplant recipients

	SUCCESSFUL TRANSPLANT (N = 31) F (%)	FAILED TRANSPLANT (N = 13) F (%)
SOCIAL FUNCTION		
SOCIAL SUPPORT		
IMPORTANT	20 (64.5)	10 (76.9)
SATISFIED	12 (38.7)	10 (76.9)*
EMPLOYED		
BEFORE TRANSPLANT	18 (58.1)	6 (46.2)
AFTER TRANSPLANT	16 (51.6)	3 (23.1)
EMPLOYMENT CHANGE		
EMPLOYED BEFORE AND AFTER	12 (38.7)	2 (15.4)
NOT EMPLOYED BEFORE AND AFTER	9 (29.0)	6 (46.1)
EMPLOYED BEFORE BUT NOT AFTER	6 (19.4)	4 (30.8)
NOT EMPLOYED BEFORE BUT AFTER	4 (12.9)	1 (07.7)
BURDEN OF SYMPTOMS		
MEDICAL/DRUG PROBLEMS	18 (58.1)	11 (84.6)†
STRESSORS/CONCERNS	24 (77.4)	6 (46.2)*
SENSE OF WELL-BEING		
IMPACT FACTORS		
ECONOMIC	8 (25.8)	0 (0.0)
DIABETIC COMPLICATIONS	2 (6.4)	4 (30.8)
PHYSICAL COMPLICATIONS	4 (12.9)	6 (46.2)
PSYCHOSOCIAL CONCERNS	7 (22.6)	0 (0.0)
REPEAT TRANSPLANT AGAIN	31 (100)	6 (46.2)‡

Significant χ^2 -relationships: * $P \leq 0.05$; † $P \leq 0.01$; ‡ $P \leq 0.0001$.

their families' time and energy than the diabetes regime.

Transplant centers should continue to merge data on prevention or reversal of secondary complications of diabetes resulting from pancreas transplantation with quality of life measures. Then decisions can be made, founded on research, where pancreas transplantation can be viewed as therapeutic in appropriately selected diabetic patients.

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