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Functional Status and Perceived Control Influence Quality of Life in Female Heart Transplant Recipients

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Background: The purpose of this study was 2-fold: (1) to describe and compare the quality of life (QOL) and psychologic well-being of 2 groups of women matched for age and functional status (6-minute walk distance), including those who had received a heart transplant and those who were candidates on a transplant waiting list; and (2) to identify correlates of QOL in female heart transplant recipients.

Methods: Data were collected from 50 female recipients (mean age 54.7 ± 13.0 years) and 50 female candidates (mean age 56.8 ± 12.2 years) from a major heart transplant facility using the Minnesota Living with Heart Failure Questionnaire, the Beck Depression Inventory and the Control Attitude Scale.

Results: The overall QOL scores were 28.0 ± 26.4 and 56.3 ± 26.1 for recipients and candidates, respectively ($p < 0.01$), with lower scores denoting higher QOL. The mean physical health (11.3 ± 11.2 vs 19.9 ± 12.1 , $p < 0.01$) and emotional health (7.5 ± 8.2 vs 12.8 ± 7.8 , $p < 0.001$) scores were also lower (reflecting higher physical and emotional health) for recipients as compared with candidates. Likewise, recipients reported significantly ($p < 0.001$) lower depressive moods (23.2 ± 8.2 vs 45.8 ± 16.3) and higher perceived control (10.9 ± 4.3 vs 8.6 ± 1.9) compared with candidates. Functional status, depression and perceived control were significant correlates of QOL among female recipients and accounted for 49% variance in overall QOL.

Conclusions: Although overall QOL of was better among female heart transplant recipients than candidates, both groups of women reported poor QOL. Clinicians need to identify potential resources and interventions to improve QOL both before and after heart transplant surgery. *J Heart Lung Transplant* 2004;23:360–367.

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Hearth transplantation is currently performed with high success rates in various centers around the world. Reports have shown that approximately 25% of heart transplant recipients are women.¹ Despite the increasing number of women needing and receiving heart transplantation, little is known about their special needs and issues related to care after transplant surgery.² Furthermore, although it has already been shown that women are at increased risk for negative outcomes after heart transplantation,² there is a paucity of research in the heart transplant literature that focuses specifically on outcomes of female patients.

Efforts to reduce death and disability in women after heart transplantation need to focus on early detection and treatment of risk factors. Although studies that focus on biologic mechanisms are needed to explain risk factors and outcomes, investigations that examine behavior and psychologic factors play an equally important role in providing additional information to advance this field of study. Such research is particularly important in heart transplant recipients, where care has evolved from focusing solely on survival to improving quality of life (QOL) and psychologic well-being.

Overall, researchers have found an improvement in QOL^{3,4} and psychologic well-being after heart transplantation.^{5,6} However, in examining gender differences, Dew and colleagues⁷ reported poorer overall outcomes (controlling for age and disease severity) in women than in men, both psychologically and physically. Women reported more depression and had poorer functional status than men. Female gender was also found to be an independent risk factor for increased risk of depression and anxiety-related disorders after heart transplant.⁸

Because QOL and psychologic well-being have been shown to increase morbidity and mortality,⁹ efforts to better understand the QOL and psychologic well-being of female heart transplant recipients is needed. Thus, the main purpose of this cross-sectional, comparative study was to describe and compare the QOL and psychologic well-being of female heart transplant recipients with a cohort of female heart transplant candidates matched for age and functional status. We also aimed to identify correlates of QOL in female heart transplant recipients. Two research questions were addressed: (1) Are there differences in QOL (overall, physical health and emotional health) and psychologic well-being (depression and perceived control) of female heart transplant recipients and candidates? (2) What factors are related to QOL of female heart

transplant recipients? Based on existing heart transplant literature, we hypothesized that female heart transplant recipients would have better QOL and psychologic well-being than female heart transplant candidates.

Assessment of QOL in female heart transplant recipients could be of benefit in predicting negative patient outcomes including depression and ineffective coping strategies. Furthermore, careful measurement of QOL and its determinants in this population would allow for the most appropriate and effective intervention to be put into place to maximize physical and emotional functioning.

METHODS

Setting and Participants

Upon approval from the appropriate institutional review board, study participants were recruited from a large transplant program and heart failure clinic at a tertiary-care medical center in southern California. A convenience sample, comprised of 50 recipients and 50 candidates, was enrolled in the study. The inclusion criteria for study enrollment were: female gender; heart transplant recipient or candidate (listed as Status 1 or 2); an orientation to time, place and person; able to read, write and speak English; and willingness to participate in the study. Patients <6 months from the date of transplant and those who were hospitalized within 1 month of study enrollment due to complications from the heart transplant or heart failure decompensation were excluded from the study. A research nurse screened potential patients who expressed an interest to participate in the study for eligibility. However, due to limitations imposed by the institutional review board, we screened and enrolled only those participants who expressed an interest to participate in the study. All patients screened met the inclusion criteria and we continued to enroll patients until we had our targeted sample.

Procedures

Once informed consent was obtained, the participants were asked to do a 6-minute walk test along an enclosed corridor of the clinic. The 6-minute walk distance served as an indicator of exercise tolerance and has been used in numerous clinical trials with high reliability and validity.¹⁰ The 6-minute walk distance has also been shown to be a strong predictor of functional status in heart failure patients.¹¹

After completing the 6-minute walk, participants were given a questionnaire packet to complete during their wait at the medical office. On average,

questionnaire completion time was 10 to 15 minutes. Three instruments were included in the questionnaire packet: the Minnesota Living with Heart Failure Questionnaire (LHFQ) was used to measure QOL, and the Beck Depression Inventory (BDI) and Control Attitude Scale (CAS) were used to measure 2 domains of psychologic well-being: depression and perceived control. In addition, participants were asked to complete a sociodemographic and medical history form.

Study Instruments

QOL, which was defined as the degree to which aspects of patients' physical, social, functional and emotional well-being are impacted by health,¹² was measured in the current study using the LHFQ. This 21-item tool asks participants to indicate the extent to which various symptoms they have experienced in the previous month have prevented them from living as they wanted. The items can be combined to form an overall QOL score as well as physical health (8 items) and emotional health (5 items) scores. The physical sub-scale contains items associated with the fatigue and dyspnea of heart failure. The emotional sub-scale consists of items such as being worried or feeling depressed. An additional 8 items include questions about other areas of life affected by heart failure and are used to compute the overall QOL score.¹³ Response options are presented as 6-point ordinal scales ranging from 0 (no) to 5 (very much), with a total maximum score of 105 (40 for physical and 25 for emotional health); a lower LHFQ score indicates better QOL. Although this instrument is a disease-specific instrument specifically designed for persons with heart failure, the emotional items are also relevant to the person after transplantation. Furthermore, the physical symptoms in the LHFQ include problems that may occur after transplantation.¹³

Psychologic well-being was operationalized as low levels of depression and high levels of perceived control. Depression was measured using the BDI, which is widely used in chronically ill populations and is well validated.¹⁴ The BDI is a self-reported inventory designed to measure severity of depressive mood or symptoms. The 21-item inventory consists of a Likert-type scale from 0 (absence of symptom) to 3 (severe or persistent presence of the symptom). Five of the BDI items pertain to somatic symptoms of depression (e.g., loss of appetite and sleep disturbance) and 16 of the items reflect non-somatic symptoms of depression (e.g., hopelessness and social withdrawal). Scores on the BDI range from 0

to 63. Patients with BDI scores of 0 to 9 are considered to have minimal symptoms of depression, scores 10 to 16 mild, scores 17 to 29 moderate, and scores 30 to 63 severe symptoms of depression.¹⁵

The CAS was used to measure perceived control. This instrument was developed to measure the degree to which respondents feel they have control (and, conversely, a sense of helplessness) related to their cardiac disease.¹⁶ Response statements are scored on a Likert scale from 1 (none) to 5 (very much). The total score range is 5 to 20, with higher scores reflecting higher (better) perceived control. We have used a similar instrument to measure perceived control in 325 cardiac patients.¹⁷ Instrument reliability as assessed by internal consistency was high with Cronbach's $\alpha = 0.89$. Cronbach's α for the current study was 0.93.

Demographic information was collected through a simple self-administered form. The form asked participants about their age, race, marital status, education, current employment status and annual income. Information pertaining to medical history (e.g., etiology of heart failure) was obtained through self-reports and verified by chart reviews. Results of diagnostic tests (e.g., echocardiogram) and information related to the participant's current clinical status (e.g., length of time since transplant, New York Heart Association [NYHA] class, ejection fraction) were obtained from participants' medical records.

Data Analysis

Data were analyzed using SPSS for Windows (version 10.0, SPSS, Inc., Chicago, IL).¹⁸ Descriptive statistics, including means, ranges and standard deviations, were used to describe sociodemographic and clinical characteristics and levels of QOL, depression and perceived control. Comparative analyses of demographic and clinical characteristics and QOL and psychologic well-being scores were computed using *t* tests or chi-square tests, depending on the levels of measurement.

We conducted univariate analyses using Pearson's product moment correlation coefficients to explore relationships between demographic and clinical characteristics (e.g., functional status), QOL scores and psychologic well-being scores, including depression and perceived control. Variables that achieved univariate significance of $p < 0.05$ were included in a multivariate analysis. A stepwise linear multiple regression was conducted to identify factors associ-

TABLE I Demographic characteristics of heart transplant candidates and recipients

Characteristic	Recipients (<i>n</i> = 50)	Candidates (<i>n</i> = 50)	<i>p</i> -value
Age, years (mean ± SD)	54.66 ± 12.98	56.79 ± 12.19	0.811
Race, <i>n</i> (%)			0.782
White	35 (70.0%)	37 (74.0%)	
Black	6 (12.0%)	7 (14.0%)	
Other	9 (18.0%)	6 (12.0%)	
Marital status, married [<i>n</i> (%)]	26 (52.0%)	27 (54.0%)	0.492
Education [<i>n</i> (%)]			0.391
≤High school	24 (48.0%)	21 (42.0%)	
Vocational or junior college	15 (30.0%)	16 (32.0%)	
≥College	11 (22.0%)	13 (26.0%)	
Employment status, employed [<i>n</i> (%)]	10 (20.0%)	10 (20.0%)	0.982
Annual income [<i>n</i> (%)]			0.136
<15,000	23 (46.0%)	18 (36.0%)	
15,000–29,999	5 (10.0%)	10 (20.0%)	
30,000–49,999	8 (16.0%)	12 (24.0%)	
\$50,000–74,999	10 (20.0%)	4 (8.0%)	
≥\$75,000	4 (8.0%)	6 (12.0%)	

ated with QOL of female heart transplant recipients. Demographic (age) and clinical characteristics (functional status) were included as covariates and were entered first. Next, to depict the impact of psychologic well-being on recipients' QOL, depression and perceived control scores were entered as a second step. Criteria for entry and removal of variables were based on the likelihood ratio test with enter and remove limits set at $p \leq 0.05$ and $p \geq 0.10$.

RESULTS

Heart transplant recipients had received their transplant, on average, 5.2 ± 4.4 years prior to data collection. Heart transplant candidates were on the waiting list, on average, 4.2 years (SD 3.8, range 1 to 12). The demographic characteristics of the 50 recipients as compared with the 50 candidates are summarized in Table I. Approximately 50% of both recipients and candidates were married and lived with their spouses. There were no significant differences in age, race, marital status, education, employment status and annual income between recipients and candidates.

The average 6-minute walk distance, which was a criterion for matching recipients and candidates, was $1,363 \pm 347$ and $1,312 \pm 299$, respectively. These means were not significantly different. We found a significant difference ($p < 0.001$) in the left ventricular ejection fraction of recipients (58.7 ± 5.3) compared with candidates (26.6 ± 7.8). There was also a significant difference ($p < 0.001$) in

NYHA class between the 2 groups of women, with 70% vs 0% in NYHA Class I, 30% vs 13% in NYHA Class II, 0% vs 53.7% in NYHA Class III and 0% vs 33.3% in NYHA Class IV, for recipients and candidates, respectively.

Table II lists the total mean scores for QOL (overall, physical health and emotional health) and psychologic well-being (depression and perceived control) for recipients and candidates. The 2 groups were significantly different on each of the QOL and psychologic well-being measure, with transplant recipients reporting better scores in all domains. We also found that 35% of both recipients and candidates reported moderate-to-severe depression. We utilized a cut-off score of 11 (based on both mean and median of the total sample of 100 women) on the CAS (i.e., <11 is low perceived control and ≥ 11 is high perceived control). Although pre-transplant patients had lower perceived control scores than their post-transplant counterparts, 26% of recipients continued to have low perceived control scores.

The correlational matrix for key variables in the study is presented in Table III. Our analyses revealed that age correlated with functional status (6-minute walk distance) and the physical health sub-scale of QOL; older participants had lower functional status and higher (poorer) physical health scores. There were no associations between the other sociodemographic characteristics (including race, marital status, education, employment status and income) and QOL and psychologic well-being

TABLE II Differences between candidates and recipients on quality of life (QOL) and psychologic well-being scores

	Possible range	Recipients (<i>n</i> = 50) (mean ± SD)	Candidates (<i>n</i> = 50) (mean ± SD)	<i>p</i> -value
LHFQ,* total	5–105	28.0 ± 26.4	52.3 ± 26.1	0.000
LHFQ,* physical	5–40	11.3 ± 11.2	19.9 ± 12.1	0.000
LHFQ,* emotional	5–25	7.5 ± 8.2	12.8 ± 7.8	0.001
Depression [†]	0–63	23.2 ± 8.2	45.8 ± 16.3	0.009
Perceived control [‡]	5–20	10.9 ± 4.3	8.6 ± 1.9	0.004

*Minnesota Living with Heart Failure Questionnaire; higher scores indicate greater symptom interference and lower QOL.

[†]Measured using the Beck Depression Inventory; higher scores indicate increased (worse) depression.

[‡]Higher perceived control scores reflect better perceived control.

scores in transplant recipients. Functional status was also significantly associated ($p < 0.001$) with QOL scores (total, physical health, emotional health) and with perceived control. Additional clinical variables, including years elapsed since heart transplant, ejection fraction and NYHA class, were not significantly related to any of the variables of interest in the study. Depression was related to overall QOL and emotional health ($p < 0.05$), but not with physical health, whereas perceived control was related to all QOL scores. Multivariate analyses revealed that functional status, depression and perceived control influenced overall QOL of transplant recipients (Table IV). These 3 predictors accounted for 49% of the variance in the overall QOL scores of the sample. Post hoc analysis was done to test for multicollinearity among the variables and demonstrated that each of the predictors had unique effects on overall QOL.

DISCUSSION

Our findings that transplant recipients had better QOL and psychologic well-being scores than transplant candidates, even while controlling for age and functional status, support our study hypothesis. Recipients in our sample had fewer symptoms limiting

their functional status (as reflected in their NYHA class) than female candidates and, intuitively, we could infer that enhanced QOL and psychologic well-being may be associated with these improvements after heart transplantation. The cross-sectional design of the study limits our ability to make deductions that would fully support this assumption. Nevertheless, we did find something of greater importance as a result of this exploratory study. We found that, despite improvements in QOL and psychologic well-being after transplantation, many women who had undergone heart transplant surgery continued to experience both physical and emotional symptoms that prevented them from living as they wanted. A significant percentage of recipients also reported high levels of depression and low perceived control.

The physical function scores of recipients suggest that they continued to experience limitations in their functional abilities after heart transplant. Because functional status of female recipients (as reflected by the 6-minute walk distance) was associated with the physical function domain of QOL and with age, and given that women in general are typically referred for transplantation when they are older,¹⁹ we postulate that decreased physical function in our

TABLE III Correlational matrix for the key variables (*n* = 50 female recipients)

Variable	1	2	3	4	5	6
1. Age						
2. Functional status	-0.337*					
3. Depression	-0.106	0.174				
4. Perceived control	-0.008	0.424 [†]	-0.256*			
5. Physical health	0.254*	-0.606 [†]	0.075	-0.508 [†]		
6. Emotional health	0.169	-0.548 [†]	0.284*	-0.548 [†]	0.717 [†]	
7. Total QOL	0.197	-0.613 [†]	0.248*	-0.575 [†]	0.944 [†]	0.873 [†]

* $p < 0.05$; [†] $p < 0.001$.

TABLE IV Predictors of overall quality of life for female transplant recipients ($n = 50$)

Variable	Adjusted R^2	F	p
Functional status	0.286	20.60	0.000
Depression	0.425	19.13	0.000
Perceived control	0.494	16.97	0.000

sample was influenced by the age of the recipients. Previous research also supports that older women are at greater risk for several conditions, including osteoporosis, simply because of their age at the time of occurrence of heart disease.²⁰ Likewise, older women are also at higher risk for side effects (e.g., weight gain, fluid retention) of chronic heart failure management and immunosuppressive therapy,²¹ which may contribute to the physical limitations experienced by women in our sample.

Our observations that female recipients continued to experience emotional distress, as reflected by high (poor) emotional health scores, support the findings of Dew and colleagues,²² who conducted a meta-analysis comparing the psychologic outcomes of transplant candidates and recipients. These investigators reported “there were no gains in the domain of psychological health; that while the functional abilities of the patients improved, their psychological states (mood disorders and emotional states) remained unchanged.” Intuitively, our findings support the presumption that, although the health status of female recipients has improved, the ongoing uncertainty, unpredictability and feelings of lack of control over their lives may continue to hinder them from living life as they want.

Our findings extend the work of Dew and colleagues by pointing to a possible mechanism for a reduced QOL, namely depression and a loss of perceived control. Two of the 3 factors influencing overall QOL, in our sample of female recipients included degree of depression and level of perceived control. Again, although recipients had lower depression and higher perceived control than candidates, we found that 35% of recipients continued to report moderate-to-severe degrees of depression and 26% reported low levels of perceived control.

The presence of depression among pre-transplant patients has been highlighted in previous research findings.^{11,23} Although patients experienced freedom from signs and symptoms and an increased ability to do activities of daily living after surgery, several patients found themselves confronted with the difficult task of adapting to a chronic physical

condition after heart transplantation with its attendant requirements for daily medication and close medical follow-up.²⁴ Dew and colleagues⁸ found that the significant benefits for women realized by 6 months after surgery was significantly lower than for men. Likewise, poor psychologic adjustment to heart transplantation was associated with reduced QOL and increased physical morbidity beyond the first 12 to 18 months after transplantation,⁸ and also among patients 5 years after their heart transplant.²⁵ The unexpected challenge that post-transplant patients need to overcome and the lack of significant psychologic benefits from the transplant may explain why women in our sample continued to experience depression.

Our findings related to perceived control are important in light of emerging literature demonstrating the prognostic implications of perceived control on QOL. Results from the current study are similar to an earlier study we conducted in advanced heart failure patients, wherein we found that perceived control was a strong predictor of QOL.²⁶ Our results also support that lack of control over significant life stresses, including financial strain, hospitalizations and life in general, may continue to raise levels of depression and affect emotional well-being. As a result, many pre- and post-transplant women never completely resume their previous roles and struggle to find meaning and purpose in life.

Additional factors such as side effects of medications that were not factored into the physical or emotional dimensions of QOL may have influenced the low overall QOL of female recipients. Likewise, because total scores on the LHFQ reflect the effects of heart disease on working to earn a living and costs of medical care, poor overall QOL in our sample of female recipients can be supported by findings that female recipients and candidates did not differ on socioeconomic measures.

The findings of this study underscore the importance of examining QOL and psychologic well-being not only among female candidates but also among female recipients. From a clinical perspective, the evidence indicates that heart transplantation is meeting the goals of improving clinical status. However, because physical function and emotional health remain low (poor), improving QOL in the patients will require that clinicians be more sensitive to the physical and psychologic needs of both pre- and post-transplant women. Strategies to improve QOL (e.g., support groups, counseling, cognitive behavioral therapy) need to be developed and tested in this patient population.

Several important limitations must be considered when interpreting the results of our study. One limitation of the study is the use of a convenience sample. Subjects volunteered to participate, and perhaps those who volunteered were different (i.e., healthier or sicker) than those who did not volunteer. Likewise, those suffering from depression may have not had the energy or motivation to complete the questionnaires. Therefore, the QOL scores may have been inflated by the self-selected sample. A second limitation involves our choice of the LHFQ to measure QOL. To increase sensitivity, we selected an instrument that was specific to patients with heart failure; however, the reliability and validity of this instrument has not been tested in the post-transplant population. Finally, the small sample size also limits generalization to all female heart transplant candidates and recipients. It should also be noted that data from our study were gathered from a primarily white sample from a single heart failure and post-transplant clinic; therefore, our findings may not generalize to other ethnic groups and patients receiving care at sites using a different medical approach.

Additional variables that may have influenced QOL and psychologic well-being, including level of social support, compliance with treatment regimens, and the potential effect of plasma catecholamines on mood status, were not measured in the current study. Likewise, it is possible that other domains of QOL that may be affected by the illness or transplant experience, including general satisfaction with psychologic, social and emotional aspects of life other than those related to health perceptions, were not included in the measures of QOL used for the study. Furthermore, the QOL measure we used was not developed for use in transplant patients and may not have captured the unique aspects of a post-transplant regimen, although it did allow comparison of the 2 groups.

Assessing QOL involves capturing all areas of life and all domains of QOL to obtain meaningful and accurate data. Future prospective, longitudinal studies that examine the relationship between other domains of QOL and additional subjective and objective variables are needed to better explicate the role of behavioral and psychologic well-being on outcomes among post-transplant women. Efforts to include women from different ethnic backgrounds and various heart failure clinics will also increase the generalizability of the findings. In addition, investigations that compare QOL and outcomes of both men and women, aimed at increasing our awareness

of potential gender biases, are also needed. Last, researchers and clinicians need to test and develop gender-specific interventions that address the needs of both men and women.

The current study extends further research in several ways. First, it clarifies the role of age on the pre- and post-transplant experience. Second, this study identifies the role of perceived control on QOL of women after heart transplant surgery. Last, we were able to clarify the role of functional status versus symptomatology in a group of female recipients and candidates.

In conclusion, we found that, although overall QOL and psychologic well-being of female heart transplant recipients were higher (better) than those of female heart transplant candidates, both groups of women in our sample continued to have low QOL and psychologic well-being scores. Our findings suggest that heart transplantation is not a cure for end-stage organ disease, but an alternative form of treatment with both potential medical and psychologic problems. Both female transplant candidates and recipients encounter psychologic problems that need to be explored further. Clinicians need to identify potential resources and assess social support of female patients before and after heart transplant. Future research into the QOL of heart transplant women should be aimed at recognizing, intervening and improving QOL and psychologic well-being. Interventions that address the specific needs of both female transplant recipients and candidates may be key to decreasing the risks for higher morbidity and mortality in this vulnerable population.

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